

Explaining the Rates and Correlates of Employment in People with Schizophrenia

Thesis submitted for PhD

University College London (UCL) 2008

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To Rosalind, Lalli and Sachin

Abstract

Background

Access to employment is poor for many people with schizophrenia despite their wish to work and we are only beginning to understand why.

Aims

1. To evaluate the current literature on the rates and correlates of employment in people with schizophrenia and the barriers to working.
2. To explore the extent to which people with schizophrenia living in the U.K., France and Germany work.
3. To explore the associations of having a job, getting a job and losing a job in people with schizophrenia living in the U.K, France and Germany.
4. To investigate whether employment status influences non-vocational outcomes.
5. To explore the views about working amongst people with severe mental illness.
6. To examine staff attitudes to people with psychosis working.

Methods

For aim 1, a literature review was completed using the PsychINFO, Embase, Medline and Web of Science Databases. Aims 2-6 were addressed using a variety of study designs. These were: quantitative analysis of data from the EuroSC study, a 2 year prospective naturalistic study of people with schizophrenia (N=1208) living in the U.K, France and Germany; a thematic analysis of semi-structured interviews with people with SMI; a survey of clinicians working in CMHTs.

Results

Aim 1 Rates of employment amongst people with schizophrenia are low. A number of socio-demographic and clinical correlates of employment and barriers to working are described.

Aim 2, 3 and 4 People with schizophrenia are able to work in all sections of the job market. Clinical, social and area-level factors have an influence on work status. Employment status may have an affect on other outcomes.

Aim 5 Participants identified advantages to working but also expressed substantial doubts.

Aim 6 Clinicians suggested that many more people with psychosis were capable of working than were actually doing so.

Conclusions

Unemployment appears to be the consequence of an interplay between the biological and social situations of service users and societal factors that affect their choices and efforts. Promisingly this also means that there are multiple points at which interventions might be effective in helping people to work.

Acknowledgements

I would like to express my heartfelt thanks to Dr Sonia Johnson, Reader in Social and Community Psychiatry at University College London for her expert guidance and availability throughout the inception and production of this thesis. I also thank Dr Johnson for her continuous support, insight and belief in my academic development. I thank Professor Paul Bebbington for his expert comments during the final stages of submitting this thesis. I am grateful to both of them for the opportunity to expand my career.

I am also grateful to Professor Paul Bebbington, Professor Matthias Angermeyer and Professor Jean-Michel Azorin, the lead investigators of the EuroSC study group and Lundbeck SA for their permission to use the EuroSC dataset for a substantial part of the analyses completed for this thesis. I am indebted to Dr Mai Stafford of University College London for her guidance on the statistical analysis in Chapter 3 and Dr Shanika Balachandra of the Camden and Islington Mental Health and Social Care Trust for aiding in some of the data collection for Chapter 7. I also thank the patients and staff who participated in all of the studies, which form the basis of this thesis.

Finally I would like to thank my wife, Dr Rosalind Marwaha without whose support, warmth, patience and encouragement, this thesis would not have been completed.

Declaration of Authorship

I Steven Marwaha confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Signed .

I have received guidance from Professor Paul Bebbington and Dr Sonia Johnson. For Chapter 2, I carried out all of the literature searches and evaluations of the studies. As explained in the Acknowledgements although I was not involved with the design or data collection of the EuroSC study a substantial amount of work was required to make the data useable. After cleaning and organization of the EuroSC data I completed all of the statistical analyses in Chapters 3 to 5. These were aided by discussions with Dr Sonia Johnson and additionally for Chapter 3 by guidance from Dr Mai Stafford of the Department of Epidemiology and Public Health at University College London

For Chapters 6 and 7, I wrote the study protocol and designed the questionnaires that were developed specifically for the study. For Chapter 6, I also carried out all of the data collection, analysis and interpretation of the qualitative interviews. For Chapter 7, I completed approximately 50% of the data collection and supervised the collection of the rest. I carried out all of the data analysis and interpretation of the analyses for all chapters.

A paper based on the literature review in Chapter 2 has been published as:

Marwaha S and Johnson S. (2004) Schizophrenia and Employment: A review. Social Psychiatry and Psychiatric Epidemiology. 39, 337-349

The investigation in Chapter 3 has been published as:

Marwaha S, Johnson S, Bebbington P, Stafford M, Angermeyer M.C, Brugha T, Azorin J-M, Kilian R, Hansen K and Toumi M. (2007). Rates and correlates of employment in people with schizophrenia living in the UK, France and Germany: findings from the EuroSC study. British Journal of Psychiatry. 191, 30-37

Finally the study described in Chapter 6 has been published and is referenced as:

Marwaha S and Johnson S. (2005). Views and Experiences of employment among people with psychosis: A qualitative descriptive study. International Journal of Social Psychiatry. 51, 302-316

These papers are presented at the end of this thesis.

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Chapter 1

Introduction

1.1 A short history of work

In modern times work has become a core part of life, providing the opportunity to fully participate in a society. The notion of work however, has been conceptualised in a variety of ways, with the value judgments made about it changing depending very often on different religious perspectives.

For example it has been suggested that within the traditional Hebrew belief system, work was seen as a punishment devised by God for the disobedience of Adam and Eve (Rose 1985). In ancient Hindu texts such as the Bhagavad-Gita written between 5000 -2000 BC work is conceptualised in a different way. One of the central messages of this book is the importance of action without attachment (Brodbeck 2004), suggesting that the type of work or action in itself is to be viewed as relatively unimportant but the mindset and motivation of the worker paramount.

During the classical period, the Greeks regarded working with disdain (Maywood 1982) and manual labour was for slaves. Aristotle's view of working was that it was corrupt and could potentially damage an individual's pursuit of virtue (Anthony 1977). The Romans adopted many of the beliefs regarding the utility or otherwise of work from the Greeks (Lipset 1990). As the amount of lands conquered by the Romans grew, the need for large scale grain production required a greater number of slaves who were very often treated as sub-human. Only specific roles in enterprises such as agriculture and big business were considered suitable for free men.

By the Middle Ages Christian thought was central in defining the norms of European society. Working and earning money became recognized as means to help those less fortunate and a way of preventing reliance on others. Thus although producing wealth became acceptable there was an expectation that

income above that required for personal subsistence was given away to charity (Hill 1996). Social status remained linked to the occupation of a person with the monastic life being of the highest order followed by agriculture. Also movement from one type of job to another was discouraged as God had determined the place of a person in the social order (Rose 1985, Braude 1975). Labour still had no intrinsic value however, being seen as a means to support ones family only.

Changes in Christian religious thought within the period known as the Reformation (16th century) are believed to be the antecedents for the perspectives on work that are prevalent in western societies today. The two key thinkers who were important in beginning these changes in attitudes were Martin Luther and John Calvin (Hill 1996). Both taught that people should work, because to do so was the will of God. The norms that developed out of their combined teachings were that working was a service to God and that people should work in their chosen occupations as opposed to their family trade, as one job was not spiritually any better than another. It was suggested that maximising income from work should be encouraged and profits were to be re-invested back into ones own business. Importantly Calvinists developed the belief that a persons' success at work was a measure of how likely they were to be part of the Elect, a group of people chosen by God to inherit eternal life.

Later in describing Christian thought during the Reformation, the German economist Max Weber coined the term the "protestant work ethic" (Weber 1904), which he argued allowed and contributed to the development of capitalism and the pursuit of material wealth in the West. He described key elements of the ethic as "diligence, punctuality, deferment of gratification and the primacy of the work domain" (Hill 1996). In the West with the passage of time these ideas supporting hard work have become secularised and integrated into social belief systems (Lipset 1990). Thus the modern situation where working is viewed as a central tenet of life is a relatively new historical phenomenon embedded in post Reformation views.

1.2 A definition of work and its functions

There are a number of potential ways to define work, such as “something we have to do” or “non-leisure activity” but these tend to unravel under close scrutiny (Haralambos et al 2004). An easily understandable and practical definition is that work is “essentially something you do for other people”. There is a technical distinction between work and employment with the latter being defined as “work you get paid for” (Boardman 2003). However outside the sociological literature the terms tend to be used interchangeably and in this thesis also work and employment are used to mean a paid job unless otherwise stated.

From a classic study investigating the impact of unemployment during the economic Depression of the 1930's, Jahoda a social scientist, suggested that employment has a manifest function of enabling a person to earn a living but also several, normally unintended but important latent functions (Jahoda 1979, 1981). These latent functions are imposing a time structure on the waking day, access to regularly shared experiences outside of the family, linking individuals to goals that are not their own, enforcing activity and defining personal status and identity. There is no reason why these functions of work should not be applicable to the mentally ill also.

1.3 The effects of unemployment on health in the general population

Unemployment is associated with poorer physical and psychological health in the general population. In the early 1970's analyses using data from a number of countries found strong correlations between unemployment rates and mortality (Brenner 1979, 1987). Although the direction of causality was subsequently vigorously debated, convincing evidence of unemployment leading to ill health has now been provided by a number of longitudinal studies.

For example in a 1% sample of census records in the United Kingdom (UK) dating from 1971 to 1981, employment was associated with lower mortality

than average. The unemployed with a pre-existing physical illness had mortality rates three times higher than the average. But, even people without a pre-existing illness who were unemployed at the census showed a 37% excess in mortality in the next 10 years (Moser et al 1987). This excess was made up of proportionately greater deaths from lung cancer, cardiovascular disease, accidents and suicide. The substantial effects on health of unemployment in Europe have been confirmed by a number of other large prospective studies (Iverson et al 1987, Stefansson 1991, Martikainen and Volkonen 1996).

Unemployment has been correlated with poorer psychological health both cross-sectionally and prospectively. In the United States of America (USA), men aged 35-60 years who became unemployed had higher levels of depression and anxiety than those who remained in work (Linn et al 1985). The relationship between poorer psychological health and unemployment appears to be dynamic and reversible. In Germany unemployed men who had higher levels of psychological distress than their working counterparts experienced a significant reduction in their distress when they re-entered the labour market or retired (Frese and Mohr 1987).

1.4 Unemployment and people with schizophrenia: the scale of the problem

Mental illnesses are among the leading causes of disability worldwide (World Health Organization (WHO) 2000), with unemployment being a usual consequence of this loss of function. In the UK whilst it is unclear if the employment rate in people with schizophrenia changed during the last decade of the 20th century the employment rate in the general population and in those with physical disabilities increased (Social Exclusion Unit 2003). Among the long term disabled, people with severe mental illness (SMI) find it more difficult to get employment than those with physical disabilities and it is only those with severe learning disabilities who are less likely to be in paid work (Social Exclusion Unit 2003).

Being out of work and its effects is not usually a short-term problem for people with mental illness and particularly for people with schizophrenia. Once established, poor occupational functioning tends to be static over many years, at least in developed countries (Reid et al 2001). In the UK once people have been on incapacity benefit for 1 year they are likely to be there for 8, and once claiming for 2 years they are more likely to die or retire on incapacity benefit than to ever return to the labour force (Department for Work and Pensions, UK, 2004).

1.5 The costs of unemployment in people with schizophrenia

Schizophrenia represents considerable costs in monetary terms to governments. The cost in 1990 in the USA was \$ 32.5 billion (Rice and Miller 1996), with a large proportion of the economic impact being due to the unemployment levels that result from this illness (Knapp et al 2004). In Australia in 2001 the total costs of schizophrenia was \$ 2 billion or 0.3% of Gross Domestic Product (GDP) with the indirect costs of people with schizophrenia not working being \$543.7 million (Killackey et al 2006). In the UK the loss of productivity due to unemployment of people with schizophrenia was estimated to be £1.7 billion in 1990 (Davies and Drummond 1994). Also approximately 40% of all disability allowance claims in the UK are on the basis of mental illness (Huxley and Thornicroft 2003).

Much more difficult to quantify but as disturbing are the personal costs of unemployment to people with schizophrenia. In the document the "Fundamental Rights of the European Union", article 15 states that every citizen of the union has the freedom to choose an occupation and the right to engage in work (European Parliament 2000). Most people with schizophrenia have no such freedom, despite the fact that the majority report a desire to work (King et al 2006, Mechanic et al 2002). As a consequence people with schizophrenia suffer a loss of status and role, are marginalized in society and are deprived of a major source of positive social identity. In short, unemployment is a considerable part of the social exclusion faced by people with schizophrenia. Also the resulting reliance on welfare benefits for

subsistence may lead to many people living just above or below the poverty line for most of their lives.

Given the psychological and social effects of unemployment on individuals with schizophrenia and the large economic costs involved, policies to improve the occupational outcomes of people with disabilities have been developed by Governments around the world. These have in the main centred, at a political level on changing social policy for people who are claiming disability welfare payments and at an individual level by providing better vocational rehabilitation services.

1.6 Social policy aimed at improving occupational outcome and reducing disability payment expenditure

Most industrialised nations have a welfare programme for people who are deemed to be “disabled” and as a consequence unable to work. In terms of policy, for the most part people with schizophrenia are usually considered within this disabled group. A wide variety of strategies have been used in order to encourage and enable people with disabilities to work and thus reduce the direct costs to the state. The discussion here is not exhaustive but an illustration of those strategies.

1.6.1 Reducing cash benefits

Subsequent to the demise of the communist government in Poland, many workers were laid off and government policy channelled these individuals in the short term to disability payments. The result of this was that disability payments in Poland represented 4.3 % of GDP in 1994 and were among the highest in Europe (Hoopengardner 2001). As a result the government tightened the rules on eligibility, requiring medical assessments to be done to evaluate the capacity to work instead of basing eligibility on the diagnosis of the recipient. Also linking payments to previous wages and indexing to overall price level and not average wages reduced the real value of welfare payments. Although this had the effect of reducing disability expenditure as a

proportion of GDP (Fultz 2003), it is unclear whether it increased employment in those categorised as disabled. Also, because of the method of indexing, this approach reduced the standard of living for those who were actually not capable of working at all.

Tightening eligibility and mandating more robust assessments of who is incapable of working are features of the new UK Welfare Reform Act 2007, which has changed the relationship between incapacity benefits and work. A claimant with schizophrenia in the UK will now face a much more stringent assessment of capacity to work and a threat of a reduction of benefits unless they are seen to be actively engaging in the process of a return to work.

1.6.2 Quotas

One way to stimulate the demand for the labour of people with disability is to create an obligation on companies to employ them. Such a requirement exists in a number of European countries meaning that companies must hire a certain percentage of people with disabilities as part of their workforce with the businesses facing an additional tax levy if they do not achieve this quota. In Germany, for example, the quota is 6% and applies to all employers with a work force of 16 or over (Bybee et al 1996). It is possible for the companies to opt out of this requirement but only by paying a levy into a special fund that supports people with disabilities in a variety of ways. Countries with widely differing economies and social structures such as China, Korea, Italy, France and Pakistan all have some kind of official quota system although many do not enforce this (Mont 2004).

1.6.3 Wage subsidies

In some countries wage subsidies are paid to employers who hire disabled workers. This can be a very effective way of reducing any additional costs to an employer whilst leaving the income received by the disabled worker unchanged. The amount of subsidy is variable but can be 100% such as in Norway and Austria. Sweden has the highest level of subsidized employment

with 1.1% of the population in 1999 being disabled workers in such work positions (Mont 2004). One potential reason for Sweden's success is the flexibility within the system. The level of subsidy received is based on the level of disability of the worker and this can change as capacity to work changes. In Sweden wage subsidy on average is 60% but can be as high as 80% (Mont 2004).

1.6.4 Antidiscrimination laws

Disability anti-discrimination law has now been adopted in most developed countries (WHO 2000). As an example, in the UK the Disability Discrimination Act 1995 prohibits discrimination against disabled people in the workplace. It also requires employers to make "reasonable adjustments" to work roles so that people with disability can continue to be employed, once recovered. It is unclear if such legislation has had any substantial effect on the numbers entering employment but most researchers agree that it is likely to be most effective at preventing people being fired from work if they develop their health problem once employment has started (Mont 2004).

1.6.5 Changing the earnings disregard

The earnings disregard is the amount of money an individual can earn before benefits are cut and there is some evidence that the level at which it is set influences the rates of employment of the mentally ill (Warner 2001). Recently in the USA, the Ticket to Work and Work Incentives Improvement Act 1999 has removed some disincentives to a return to employment partly by increasing the amount of money disability welfare recipients can earn before loss of payments and medical benefits. This offers more scope for people to test work out, whilst not losing the security of benefits before a full transition is made into employment. This Act also promotes access to vocational services.

1.7 Service models aimed at improving employment outcomes

Traditionally work schemes were linked to the large mental asylums as part of the industrial therapy units. These provided daytime activity in a work setting paying its attendees a nominal wage. Deinstitutionalization has resulted in the development of a broad range of employment schemes for people with mental illness, although they can largely be categorized into sheltered employment, supported employment and social firms (Crowther & Marshall 2001, O'Flynn & Craig 2001).

Sheltered employment workshops resemble industrial therapy units and aim to provide “meaningful daytime activity” within a separated work setting for the mentally ill (Gurvey & Bedell 1994). Many schemes run on these lines are referred to as providing pre-vocational training, that is, employment experience that may eventually lead to open market job acquisition. Social firms are not for profit businesses created solely for the employment of people with disabilities and are common in Europe (Warner & Mandiberg 2006). Associated with social firms is the Clubhouse model, which arose over 50 years ago as a means to foster patient autonomy in a setting, which is not “psychiatric”. In the clubhouse building, staff and clients meet for mutual support and the organization also offers paid transitional work controlled by the clubhouse (Beard et al 1982, Hill & Shepherd 1997).

Supported employment has its origins in service provision for those with substantial learning disabilities (Anthony and Blanch 1987). It originated in the US and has been most clearly manualised as the Individual Placement and Support (IPS) model. The core features of IPS are: to help patients get and maintain their chosen job on the open labour market with little or no pre-application training; the rehabilitation service is integrated into general mental health services; services and job seeking are moulded to fit patient choices and preferences; assessment of work skills are continuous and based on work experiences; and work related support is indefinite (Becker et al 1994).

The IPS model has risen to prominence remarkably quickly and there is now a substantial body of research largely based in the US describing its efficacy (Crowther 2001). The only European study published to date (Burns et al 2007) also supports the effectiveness of IPS, in comparison to services that concentrate on providing pre-vocational training.

1.8 Aims of the thesis

There are significant personal and social consequences of unemployment in people with schizophrenia, a large financial cost to society and rapidly increasing political interest at both the national and international level in improving occupational outcomes. Thus, there are compelling reasons for carrying out research to aid our understanding of the extent to which people with schizophrenia work and the factors that facilitate or impede working. Also the delivery of mental health services has changed markedly over the past 50 years across the developed world (Geller 2000) but the effect of this on the occupational functioning of people with schizophrenia is unclear. We know relatively little about employment in people with schizophrenia in recent times, its variations between countries, or the factors associated with having or losing a job.

We are only beginning to understand the barriers to work that people with schizophrenia face. A more thorough understanding of all of these issues would be valuable in informing both the development of local vocational services and national mental health and social policy. Knowledge of whether employment affects other outcomes that are important to clinicians and patients would add value to these policy debates also. This thesis is intended to address some of these issues.

Thus the aims of this thesis are:

1. To describe and evaluate the current literature on the rates and correlates of employment status in people with schizophrenia and the barriers to working that these people face.
2. To explore the extent to which people with schizophrenia living in the U.K., France and Germany work.
3. To explore the factors associated with having a job, getting a job and losing a job in people with schizophrenia living in the U.K, France and Germany.
4. To investigate whether employment status influences psychotic and depressive symptom severity, subjective quality of life and general levels of functioning in people with schizophrenia living in the U.K, France and Germany.
5. To explore the views and experiences of working of people with severe mental illness.
6. To examine staff attitudes to people with psychosis working

These aims will be addressed in the following ways

Aim 1

Chapter 2 will describe a review of the current literature on the rates of employment and factors associated with working in people with schizophrenia. Previous studies will be critically reviewed and used to summarise the range of employment rates described internationally. Cross sectional and prospective studies reporting the correlates of working will also be evaluated with a view to assessing which factors are most consistently detailed as important. Studies reporting the effects of employment on a range of other outcomes will be examined and where possible the potential direction of causation discussed. The literature on the barriers to working that people with schizophrenia face will be summarised. Throughout the review particular attention is paid to gaps in the literature, some of which further chapters in this thesis seek to address.

Aim 2

Chapter 3 will describe an analysis of the rates of employment and types of occupation of people with schizophrenia living in the UK, France and Germany using the baseline cross sectional data from the EuroSC study, a 2 year cohort naturalistic investigation of people with schizophrenia. Variations in employment between countries and individual study centres will be discussed and possible reasons for differences examined.

Aim 3

In order to understand the factors associated with having a job, the cross sectional dataset of the EuroSC study will be analysed using a logistic regression and this will be discussed in Chapter 3. The 2-year dataset is used to explore the correlates of getting a job and losing a job prospectively in Chapter 4, again using regression analyses.

Aim 4

The analyses in Chapter 5 will explore whether employment status is associated with changes in general levels of functioning, degree of psychotic and depressive symptoms and quality of life in people with schizophrenia. Multiple and logistic regression modelling will be carried out using the 2-year EuroSC dataset. Separate analyses will be completed for each of the outcomes of interest.

Aim 5

In Chapter 6 an account will be given of a qualitative study concerning the views and experiences of people with severe mental illness with regard to working. This study uses a thematic analysis to explore in detail the motivations of people to work and the barriers that they face. Participants'

views of factors that would facilitate a return to employment will also be examined.

Aim 6

Chapter 7 will describe a questionnaire study of the views of staff from community mental health teams (CMHTs) in North London with regard to the employment of people with psychosis. The results will be interpreted in the light of patients' experiences of working and the wider literature.

In Chapter 8 the conclusions that can be drawn from this series of analyses will be examined, linking them to explore the potential explanations of the rates and correlates of employment in people with schizophrenia and the factors facilitating and impeding work.

Chapter 2

A review of the rates of employment and factors associated with working in people with schizophrenia

2.1 Introduction

In this Chapter, I address Aim 1 of this thesis. I describe the method and results of a review of the current literature aimed at answering a number of questions about the rates of employment, its correlates and whether employment is associated with other outcomes in people with schizophrenia. Although the review is essentially narrative, the methodological procedures were intended to be reproducible and to achieve comprehensive coverage of the current literature.

In order to understand whether rates of employment are dependent upon the stage of illness, studies of people with first episodes of psychosis were examined in addition, but separately from studies of people with established schizophrenia. Using the UK as a case study, a comparison is made between the rates of employment in people with schizophrenia and the employment rate in the general population over the last 50 years. I also address and examine the main barriers to working that people face. The results of this review were then used to generate the research questions and inform the interpretation of the analyses described in Chapters 3 to 7.

2.2 Aims of the Literature review

This review aims to answer the following questions

- What is the employment rate in people with established schizophrenia?
- How does this compare to the rate reported in first episode studies?

- What is the relationship between variations over time in the employment rate among people with schizophrenia and among the general population?
- What are the factors that are associated with employment status among people with schizophrenia?
- Does employment influence other outcomes in people with schizophrenia?
- What are the barriers to employment?

2.3 Method

2.3.1 Search strategy

A literature search was conducted using the Medline (1966- 2007), EMBASE (1980 - 2007), CINHAHL (1982 - 2007), Psych Info (1882 – 2007) and Web of Science databases, restricted to reports published in the English language. All searches used several of the permutations of the following base keywords to identify papers discussing schizophrenia and employment: *schizophrenia*, *work*, *employment*, *occupation*, *vocation* and *job*. Although the main focus of this thesis is people with schizophrenia, the search terms *psychosis* and *severe mental illness* were added with the aim of identifying specific information for schizophrenia within the studies that used these diagnostic categories.

The basic search terms above were then used in conjunction with others to retrieve papers that addressed the aims of the literature review more specifically. These further search terms were *prevalence*, *epidemiology*, *cross sectional*, *rate*, *incidence*, *demographic*, *first episode*, *early intervention*, *correlates*, *association*, *predictors*, *barriers*, *benefits*, *welfare* and *views*.

The search included original papers and previous reviews on the subject. Reference lists in all directly relevant papers were checked for further sources. The names of major epidemiological studies conducted in the last fifteen years

were identified with expert help, searched for, and information on employment retrieved if possible. A brief Internet search was also conducted using the *Google* engine.

2.3.2 Assessment of papers retrieved

Large numbers of references were generated by this search strategy. Papers were assessed on their relevance to the literature review aims and a decision made on their inclusion. Not every relevant paper found is cited in this review. Rather judgments have been made such that studies that are more methodologically robust, that have used standardized instruments and with larger sample sizes have been cited in preference to others.

Because the employment rate of people with schizophrenia was expected to be low, only studies with a sample size of around 200 or more were initially included to ensure that interpretation of the rates was on a robust basis. In order that an assessment could be made of any trends in employment rates in the U.K over the last 50 years or so, smaller studies carried out before 1985 were included because of the very limited number that fulfilled the larger sample size criterion. No sample size limits were set for the first episode psychosis search, as samples of incident cases are normally relatively small.

2.4 Results

2.4.1 Types of study found

The studies found were published between 1958 and the present day. There appeared to be an increasing number of relevant reports published in the last 10-15 years, perhaps reflecting an increasing interest in the employment of people with schizophrenia.

Overall there were surprisingly few studies that specifically reported the employment rate of people with schizophrenia. Work was often not the primary focus of many of the studies retrieved, but employment data were

described as part of the basic demographic details of the sample for the study. There were very few epidemiological studies designed to investigate employment and its associations in a thorough manner. Because of this, those that did are mentioned several times in the relevant sections below.

A number of different types of study design reporting relevant results were obtained by the search strategy. These are outlined here but discussed further in the appropriate sections in the text below. Firstly there were a number of Randomised Controlled Trial's (RCTs) and observational studies seeking to demonstrate the efficacy of a vocational programme. The participants in these studies frequently represent a self-selecting group of people with schizophrenia committed to obtaining a job. These studies were not used to describe the employment rate but did provide significant information on the correlates of employment.

National household surveys reporting the rate of employment in people with schizophrenia or psychosis were also retrieved. These were based in the UK, USA and Australia and their possible limitations are that the number of cases of psychosis identified was small and that the diagnosis of schizophrenia was self-reported. Finally there were a number of large cross-sectional and naturalistic observational cohort studies of people with schizophrenia sampled from the community population of an area. Frequently these epidemiological surveys were designed to answer a variety of different research questions often unrelated even to the social outcomes in schizophrenia.

2.4.2 Difficulties in interpretation

Because of the different types of research methodology, recruitment and study setting, direct comparisons between studies were often difficult to make. An additional issue was the diagnostic category under consideration. Some of the studies had samples in which there was no description of diagnosis further than "psychosis" although others gave rates for sub-categories. Also in some cited reports participants were described as having severe mental illness, again without further distinguishing diagnosis. Samples of the severely

mentally ill in the USA tend to include substantial numbers of people with major depression (Cook et al 2006) as well as psychotic disorders such as schizophrenia. This is because US-based studies tend to apply a US Federal government definition of SMI, which is linked to benefit entitlement. This may be different to how the term is defined in Europe where samples of people with SMI do not usually contain significant numbers of people whose diagnosis is major depression.

There is no standard method of describing employment in people with schizophrenia and in most studies it is unclear what definition has been used. Thus in some studies it is unknown whether the rate reported is for open, sheltered, voluntary, part-time or full-time employment and also how far definitions require sustained attendance at work for people to be categorised as employed. Because employment is not defined in the same way in every study, it is more difficult to reach an understanding of the commonest and most robust factors associated with working. An example of this is when employment outcome is defined in two different ways such as “competitive employment” and “working > 40 hours/ month” in many RCTs of IPS. Whilst both may be important outcomes when assessing the efficacy of an intervention, separate analyses of the associations of employment defined in these ways can at times give discrepant results (Burke-Miller et al 2006).

There is often very little mention of what sort of work people are engaged in and whether this is for an open market rate of pay. This was the case particularly for older publications. Also the majority of reports do not explain how they classify women who are working in the home, who may be described as working especially in some recent studies. Indeed, large international variations in the female employment rate in the general population (OECD 2007) create difficulties in interpretation of international comparisons of employment rates among the mentally ill.

The unemployment figures also are difficult to interpret since some rates may refer only to those who are looking for work and others may include the long-term disabled claiming sickness benefit or pensions. This is one reason why

employment rather than unemployment rates are discussed where possible in this review.

2.4.3 What is the rate of employment in people with schizophrenia?

2.4.3.1 European studies

Table 1 shows the European studies that report employment rates in people with schizophrenia. The open market employment rate is quoted wherever possible and it has been made clear when this is not the case. The U.K studies are ordered by the year of data collection in order to indicate how rates may have changed over time in this country (see section 2.4.5). Nearly all the studies found which reported employment rate were epidemiological surveys of people with schizophrenia living in the community or people discharged from hospital. The sampling frames of the studies were however different, acquiring participants from mental health services, psychiatric case or GP registers or at the point of hospital discharge.

In the U.K, overall the range of employment rates was between 4% and 60%, although most studies up to the 1990's report a rate of around 20% to 30% among people with schizophrenia. Older studies (Johnstone 1991) and those that sampled from relatively affluent areas tend to report higher rates of employment. As expected the lowest rates are found in studies that solely sampled people under the care of psychiatric community mental health teams (Perkins and Rinaldi 2002).

Table 1: European studies reporting employment rates

Author	Year/s of data collection	Sample size N=	Location / Setting	Sampling frame	Diagnostic category	Employment rate
Brown et al 1958	1950's	229	London, U.K	Discharges from inpatient units	SMI: 2/3 with Schizophrenia	41%
WHO 1973 International Pilot Study of Schizophrenia	1968	Total sample: 1202 Aarhus: 129 Agra: 140 Cali: 127 Ibadan: 145 London: 140 Moscow: 140 Taipei: 137 Washington: 132 Prague: 125	Aarhus (Denmark) Agra (India) Cali (Colombia) Ibadan (Nigeria) London (UK) Moscow (Russia) Taipei (Taiwan) Washington (US) Prague (Czechoslovakia)	Psychiatric centre	Schizophrenia	Aarhus 65% Agra 57% Cali 54% Ibadan 57% London 60% Moscow 90% Taipei 40% Washington 55% Prague 70%
Cheadle et al 1978	1974	190	Manchester U.K	Salford case register	Schizophrenia	26%
Morgan and Gopaldaswamy 1983	1970's	156	Unknown U.K	Discharges from hospital	Long stay patients (primarily those with schizophrenia)	26%

Author	Year/s of data collection	Sample size, N=	Location / Setting	Sampling frame	Diagnostic category	Employment rate
Kelly et al 1998 Nithsdale Schizophrenia survey	1981	133	Scotland, Nithsdale (rural) U.K	Range of health and social care services	Schizophrenia	19%
Gibbons et al 1984	1982	362	Southampton U.K	Inpatients	Schizophrenia	20%
Johnstone 1991	1985	342	Harrow, London (suburban) U.K	Inpatient and day services	Schizophrenia	31%
Harvey 1996. Camden Schizophrenia Surveys	1986	528	Camden, North London. (urban) U.K	Range of health and social services	Schizophrenia	19%
Perkins and Rinaldi 2002	1990	1015	Wandsworth, South London (urban) U.K	Community mental health and rehabilitation teams	Severe mental illness: Schizophrenia	12%

Author	Year/s of data collection	Sample size N=	Location / Setting	Sampling frame	Diagnostic category	Employment rate
Jeffreys et al 1997	1991	588	Camden, North London (urban) U.K	Range of health and social services	Schizophrenia, Schizo-Affective disorder, Delusional disorder	14%
Thornicroft et al 1998. PRISM study	1991-1992	514	South London (Urban/suburban) U.K	Range of health and social services	Psychosis	16%
UK700 Group 1999	1993?	708	London: Manchester 3:1(urban) U.K	Mental health services	Psychosis	20%
Foster et al 1996	1993-1994	470	England U.K	Community and mental health services and institutions	Psychosis	Private households: 21% Institutions: 12%
Kelly et al 1998 Nithsdale Schizophrenia survey	1996	168	Scotland, Nithsdale (rural) U.K	Range of health and social care services	Schizophrenia	8%

Author	Year/s of data collection	Sample size, N=	Location / Setting	Sampling frame	Diagnostic category	Employment rate
McCreadie 2002 Scottish Comorbidity Study Group	1999-2000	316	Scotland (UK) Nithsdale/ Aberdeen/ Glasgow	Key informant method. Range of health and social care services	Schizophrenia	8%
Perkins and Rinaldi 2002	1999	1015	Wandsworth, South London (urban) U.K	Community mental health and rehabilitation teams	Severe mental illness: Schizophrenia	4%
Bebbington et al (2005). EuroSC	1998-2001	Total sample: 1208 France: 288 Germany: 618 Britain: 302	Europe France Germany London	Mental health services	Schizophrenia	Total sample: 20.1%
O'Brien et al (2003). Psychiatric morbidity in Great Britain	2000	200	England U.K	Community survey and GP database	Psychosis	27%

Author	Year/s of data collection	Sample size, N=	Location / Setting	Sampling frame	Diagnostic category	Employment rate
Middelboe et al 2001	Not described	418	Nordic Countries	Out-patient register	Schizophrenia	12%
Borga et al 1992	1984	237	Stockholm	Case register, health and social care services	Schizophrenia	17%
Honkonen et al 2007	1989 1993 1997	771 736 661	Finland	Finnish Hospital discharge registers	Schizophrenia	7.4 % 2.6% 1.5% Overall: 4%
Gaite et al 2002. EPSILON	1998	404	Europe	Mental health services	Schizophrenia	Total: 20% Copenhagen 35.3% London 8.3% Amsterdam 13% Santander 14% Verona 30%

Author	Year/s of data collection	Sample size, N=	Location / Setting	Sampling frame	Diagnostic category	Employment rate
Haro et al 2003 SOHO study	2000-2001	10205	10 European countries	Referral from a treating psychiatrist	Schizophrenia	Overall rate: 23.5%
Lambert et al 2006 German sample of the SOHO study	2000-2001	2960	Germany	Referral from a treating psychiatrist	Schizophrenia	42.6%

Most UK studies carried out after 1990 report employment rates of 10-20% with figures varying between 4% and 27%. The higher figure of 27% is from the Psychiatric Morbidity in Great Britain Survey (O'Brien et al 2003). This was a household survey of people living in the community with a psychotic disorder, which was then augmented by a supplementary sample obtained from the General Practice Research Database. The survey took considerable steps to ensure a representative sample and had adequate sample size (N=200). The sample however was heterogeneous including people with schizophrenia or bipolar affective disorder. People with affective disorders tend to have higher rates of employment than those with schizophrenia (Bland et al 1998) and the pooling of people with both disorders may explain the outlying rate. However, it may also be the case that this study successfully sampled the full range of people with SMI, some of whom are unlikely to have much contact with psychiatric services because they are working.

Employment data regarding people with disabilities are collected as part of the UK Labour Force Survey (LFS), a regular household survey of a sample of the general population, used primarily to provide labour market statistics. The mental health problems causing "disability" are self-reported, and in 2001 this survey reports the employment rate for those with a disability classified into "depression and bad nerves" as 22.2% and those with "mental illness, phobia, panic" as 10.4% (Smith and Twomey 2002). Because of the lack of diagnostic clarity this information is not included in the table or analysed further.

Two studies based in London and one in Scotland that report rates from a single centre at two time points suggest a decrease in the employment rate in people with schizophrenia over time. In a 10 year series of annual cross-sectional surveys of patients with long term mental health problems in Wandsworth, London (Perkins & Rinaldi 2002) employment among people with schizophrenia decreased by 8% from the already low rate of 12% between 1990 and 1999. The Camden Schizophrenia Surveys, which used a wide ranging and exhaustive sampling strategy to gather information on all prevalent cases of schizophrenia in a geographically defined area at two points in time (Harvey 1996, Jeffreys et al 1997), found the employment rate

had dropped from 19% to 14% in 5 years. The employment rate in people with schizophrenia in two cohorts of the Nithsdale schizophrenia surveys also fell from 19% in 1981 (N=133) to 8% in 1996 (N=168) (Kelly et al 1998). Although neither cohort in this latter study had a sample size over 200, case ascertainment in both years used the same methodologically robust strategy.

If the UK results are excluded, rates reported in European studies range from 1.5% - 43%; a greater variation than in recent UK based data, although the smaller number of reports limits this observation. Studies that sampled people in similar ways across European areas provide important insights into the nature of the variation. Thus the European Psychiatric Services: Inputs Linked to Outcome Domains and Needs (EPSILON) study which recruited a large representative sample (N=404) of people with schizophrenia in contact with psychiatric services in five European countries reported a significant difference in the rates of employment across centres. Although employment is not operationally defined in the published paper rates were very low in London (8.3%) but more than 4 times higher in Copenhagen (35%) (Gaite et al 2002). Similarly in the Schizophrenia Outpatient Health Outcomes (SOHO) study, which recruited over 10,000 people from 10 areas in Europe, there appears to be variation in the extent to which people are working. Although data on employment rates by country have yet to be reported, the average rate was 23.5% (Haro et al 2003) whereas the rate in Germany was 42.6% (Lambert et al 2006). Again employment was not defined so it is difficult to know what type of work is being described.

A striking outlier in the European employment data is the recently published results from the Finnish Psychiatric Discharges Register (Honkonen et al 2007). Three cohorts of people with schizophrenia (total N=2168) who had an average illness length of 15 years were interviewed 3 years after discharge from hospital. The rates of competitive employment were 7% in 1989, 2.6% in 1993 and 1.5% in 1997. The authors suggest that the very low rates of employment were because of the long average illness length in the sample and because employment was strictly defined as open market work. There was a downward trend in rates of employment over time.

2.4.3.2 North American and Australian studies

Table 2 summarises the North American studies reporting employment rates that were retrieved by the search strategy. Additionally an Australian study is included in the table, which reports an employment rate that is not markedly different to those in the USA.

The employment rate reported amongst people with schizophrenia in the USA ranges from 3% to 42.8%. The Epidemiological Catchment Area Study (Robins and Regier 1991) reports the highest rate although the diagnostic method and the exclusion of participants without a stable residence may have over-represented those with a good prognosis (Commander & Odell 2001, Mortensen & Juel 1990). The National Co-Morbidity Survey (Kendler et al 1996) reports a similarly high rate of employment (53%), though the sample of people with schizophrenia (N=74) was small and there was a high level of false positives on the screening tool used.

Mechanic et al (2002) report employment data analyses from the National Health Interview Survey on Disability 1994/1995. This was a national US household survey with a total sample size of approximately 120,000 non-institutionalised individuals living in the USA. Diagnosis of schizophrenia was self-reported and the authors acknowledge that bias may have been a factor in their results. They suggest, "Unemployed persons may report more illness and disability than their objective symptoms warrant as a way of justifying their employment status to themselves and others". The employment rate (defined as any paid work in the last 2 weeks) of people with schizophrenia (N=302) was 22.5%, with this figure dropping to 12% if employment was defined as working more than 35 hours / week.

Table 2: American and Australian Studies reporting employment rates

Author	Year/s of data collection	Sample size, N=	Location / Setting	Sampling frame	Diagnostic category	Employment rate
Robins and Regier 1991. Epidemiological catchment area survey	Started 1980	Total sample 20,000. Lifetime diagnosis of schizophrenia: 305	USA	Large scale community sample	Schizophrenia	42.8%
Mechanic et al 2002 National Health Interview Survey on Disability (NHIS-D)	1994 / 1995	Total community sample: 120,216 Self reported Schizophrenia: 320	USA	Large scale national sample of non-institutionalized people	Schizophrenia	Any employment in last 2 weeks: 22.5% > 35 hours / week: 12%
Mueser et al 2001.	Not described	528	Multi-centre, USA	Mental health services	Schizophrenia	9.7%
Mowbray et al 1995	Not described	304	Michigan, USA	Community mental health teams	Severe mental illness 70% of sample had schizophrenia	40%

Author	Year/s of data collection	Sample size, N=	Location / Setting	Sampling frame	Diagnostic category	Employment rate
Drake et al 1998	1990 1995	> 2,000	New Hampshire, USA	Community mental health centres	Severe mental illness. More than 50% with schizophrenia	1990: 7% 1995: 24%
Lutterman et al 2003	1998	11 states in USA	Multiple states	Public mental health systems including community mental health centres	Schizophrenia	2.8% to 18.4%
Rosenheck et al 2006 CATIE study	Not described	1,400	USA: Multi- centre	Community Psychiatric services	Schizophrenia	Competitive employment: 14.5% Non-competitive employment: 12.6%
Salkever et al 2007 US SCAP	1997-2003	2,326	USA: Multi-centre	Organized Healthcare systems:	Schizophrenia, Schizophreniform and Schizo-affective disorder	Any paid work 17.2%

Author	Year/s of data collection	Sample size, N=	Location / Setting	Sampling frame	Diagnostic category	Employment rate
Pandiani et al 2004	2001	2,938	Vermont	Operational county wide databases	Severe and Persistent Mental Illness	Schizophrenia sub sample: 24% Other diagnoses: 34%
Gureje et al 2002	1997	582	Australia	Range of health and social care services	Schizophrenia	23.7%



More recently the Clinical Antipsychotic Trials of Intervention Effectiveness (CATIE) study, designed to investigate the pharmacological effects and cost effectiveness of typical and atypical drugs used a rigorous methodology to identify 1400 people with schizophrenia from multiple states in the USA who were living in the community. In this sample 72.9% reported no employment, 14.5% were in competitive employment and 12.6% in non-competitive employment (Rosenheck et al 2006). Competitive employment was defined as having any paid job for any number of hours that earned any income in the last month, a very inclusive description of work.

Broadly similar employment rates were obtained in a naturalistic observational multi-site study of 2326 people with either schizophrenia, schizophreniform or schizoaffective disorders (Salkever et al 2007). Participants who were randomly selected from veterans affairs service providers, community mental health teams, public psychiatric hospitals and University out-patient departments were annually assessed over a 3 year period. Employment rate varied depending on the definition of work that was used. Thus 17.2% had done some type of paid work in the last month, 14.2% had done some paid work remunerated at above the minimum wage and 9.7% were working and being paid at at least the level of the minimum wage for more than 40 hours in the last month. It is noteworthy that amongst those classified as employed using a broad definition (17.2%) less than 15% reported working more than 35 hours /week, suggesting that much of the employment was transitory and part-time.

Analysis of the large database of the Sixteen State Study on Mental Health Performance Measures (Lutterman et al 2003) suggest state-wide competitive employment rates in people with schizophrenia (results from 11 states) vary between 2.8% and 18.4% with the median being 11.4%. The sixteen state study was designed to develop and apply comparable performance and outcome indicators on public mental health systems in multiple states. Employment was defined as working full or part-time at the last assessment by mental health services. These figures are similar to the employment rates from a statewide register of people with SMI in New Hampshire's 10

community mental health centres (Drake et al 1998). Between 1990 and 1995 the employment rates increased in this area, probably because of the increasing emphasis of the IPS model of job placement in New Hampshire.

2.4.3.3 Asia and other countries

Only a limited number of studies were found that originated from developing nations, a possible bias created by an English language literature search. Those retrieved that did examine employment, reported rates that were generally higher than in western countries although sample sizes were often small.

A follow up study of people with schizophrenia in India found that occupational outcome was “good” in 53% of patients after 10 years (Srinivasan & Thara 1997). The sample size was small at 40 and was all male, but the authors comment that the “compelling need for men to be the wage earners in the Indian situation” may underlie this finding. This high rate of employment may also be related to the nature of available employment in that there may be more entry-level jobs in a developing economy.

In a cross sectional survey of 200 people with schizophrenia living in Malaysia who were sampled from out-patient clinics, the overall employment rate was 26% but there was a significant gender difference with the rate in men being 37% but only 15% in women (Mubarek 2006). Similar to the hypothesis suggested by Srinivasan & Thara (1997), the author of this study comments that there is a strong cultural expectation for men to be breadwinners in Malaysia and overall it was likely that women sampled for the study were being deprived of the opportunity to work despite having lower overall disability levels.

The only relevant African study found was conducted in Nigeria and had a combined sample of people with schizophrenia and affective disorders (N=135). Diagnosis was made by applying the International Classification of Diseases (ICD) version 10 (WHO 1992a) criteria and efforts were made to

make the study sample as representative as possible of people seen in clinics at the University teaching hospital. Participants were excluded whose onset of illness was less than 2 years previously. The employment rate for the total sample was 52% at the onset of illness and 57.8% at the time of the study (Makanjuola et al 2007).

World-wide data on employment rates was provided by the International Pilot Study of Schizophrenia (IPSS) (WHO 1974), which reported a strikingly large variation of rates ranging from 40% in Taipei to 90% in Moscow. These rates are surprisingly high by today's standards and this may in part be due to the sampling strategy used in the study. The samples were of people with psychosis, weighted towards recent onset cases (within 5 years of study entry) who had not been hospitalised for more than 2 out of the previous 5 years, rather than the full range of schizophrenia cases. Therefore the sample may have excluded people with chronic schizophrenia with a poorer outcome.

Another potential reason for the particularly high rates in some centres may be the social, political and economic environment in the countries at the time. For example the former communist regimes such as Moscow and Czechoslovakia reported very high rates of employment in schizophrenia. In these countries during the period of data collection neither was unemployment officially acknowledged or reliable national statistics collected. People may also have been under-employed, in the sense that they were doing work with no real purpose or which took up very little of their official working day (Porket 1989).

In the Taipei sample of the IPSS study the employment rate is reported to be at the lower end of the range at 40%. This rate represents employment of people with schizophrenia early in the course of the Chinese Cultural Revolution (1964-1976). During this period manual work and rural farming were considered to be crucial treatments for mental illness, which by some was believed to be due to capitalistic thinking. It is thus surprising that the rates were not very much higher.

From this limited evidence it appears that in developing countries that may lack a substantial government funded welfare system, there may be generally higher rates of employment in people with schizophrenia in comparison to countries with “developed” economies.

2.4.4 How do the employment rates compare in established schizophrenia and in first episodes?

As well as the methodological problems in comparing studies, which have been discussed in section 2.4.2, there are additional difficulties in the comparison of studies of incident cases of psychosis. There is a lack of consistency in the time period used to define whether a person is employed at onset of illness. For example some studies may classify people as working only if they still have a job at the time of the onset of psychosis or first presentation to services, while others may code people in work within the previous year. This is frequently not made clear and therefore it is difficult to know if the reported employment rate is a pre-morbid or morbid description or if in fact the category of employed traverses both periods.

Also it is likely that over time there has been a change in the nature of the diagnostic groups included in these studies. People in older studies are more frequently described as incident cases of schizophrenia whereas many of the more recent reports concern the presentation to specialist early intervention services of people with psychotic symptoms. Thus, these more recent studies may include people with Bipolar Affective Disorder, Schizophrenia or people with brief psychotic episodes.

Table 3 shows the first episode studies that report employment rates, again shown by year of data collection where available. The range of reported employment rates found was 23% to 65% in studies published between 1980 and 2007.

Table 3: First episode studies reported employment rates

Author	Year of data collection	Sample size	Location	Sampling frame	1st episode defined as	Employment rate
Schwarz et al 1980	1978	70	Mannheim, Germany	In patient and outpatients	1 st presentation to services	43%
Johnstone et al 1986	1979-1982	253	Harrow, London	Hospital	No previous psychosis. No neuroleptic and admission for > 3 days	At baseline 65% At two year follow: 49%
Birchwood et al 1992	1984-1986	154	Birmingham UK	Hospital	1 st hospital admission	52% At 12 month follow-up 25%
The Scottish schizophrenia research group 1992	Unknown	49	Scotland	Hospital	1 st hospital admission	43% At 5 year follow-up 20%
Vazquez-Barquero et al 1995	1989	86	Cantabria, Spain	Mental health services	No previous episode	49%
Byrne et al 2002	1981-1998	7704	Denmark	Danish Psychiatric Central case register	1 st contact	23% within one year of contact

Author	Year of data collection	Sample size	Location	Sampling frame	1st episode defined as	Employment rate
Bhugra et al 1997	1991-1993	White: 38 Asian: 24 African-Caribbean: 38	London, U.K	Mental health services	1 st contact	White: 31.6% Asian: 29.8% African-Caribbean: 13.2%
Bhugra et al 2000	Unknown	Trinidad: 46	Trinidad	Mental health services	1 st contact	Trinidad: 65%
Singh et al 2000	1992-1994	166	Nottingham, U.K	Psychiatric services	1 st contact with services	25% At 3 year follow up: 16%
Barnes et al 2000	Unknown	53	West London U.K	Hospital	1 st admission	13% within one year of admission
Sim et al 2006	2001-2003	Total: 142 46 with psychiatric co-morbidity 96 without psychiatric co-morbidity	Singapore	Hospital	1 st admission	56.5% 58.3%

Author	Year of data collection	Sample size	Location	Sampling frame	1st episode defined as	Employment rate
Skeate et al 2002	Unknown	42	Birmingham UK	Community mental health teams	Unknown	40%
Addington et al 2003	Unknown	177	Calgary Canada	Presentation to an early intervention service	1 st presentation to early intervention service	Baseline: 29%
Lambert et al 2005	1998-2000	643	Melbourne, Australia	Presentation to an early intervention service	1 st presentation to early intervention service	Work / school 49.8%
Payne et al 2006	1993-1995	146	London and Middlesex Ontario Canada	Hospital	1 st admissions	25.4%
Rosen & Garety 2005	1980-1991	436	Oxford, UK	Oxford record linkage system	1 st presentation to services	Single episode: 61.3% Multiple episodes: 37.2%

Author	Year of data collection	Sample size	Location	Sampling frame	1st episode defined as	Employment rate
Novick et al 2007 SOHO study	2001	1009	10 European countries	Presentation to out-patient settings	Previously untreated with anti-psychotics	At baseline: 33.7% At 2 years: 34.7%

These studies show higher employment rates than those for established cases of schizophrenia, but with some overlap, especially for more recent samples where rates are sometimes relatively low. It is striking that, in most studies, the majority of people presenting to services for the first time are already unemployed.

As in the studies of prevalent cases of schizophrenia, there does appear to be an association between year of data collection and employment rate, with older studies reporting higher rates, often around 50%. Thus Johnstone et al (1986) report the employment rate as 65% in 1979 from a sample of over 250 people in North London, UK. Although it has a smaller number of participants (N=100), another study based in London and recruiting in 1991 reports the employment rate as approximately 25% (Bhugra et al 1997). Such comparisons are limited by differing study methodology inclusion criteria. How urban the setting is may also be different and this may in itself influence the employment rate (Drake et al 1998).

Though similar caveats apply it also appears that there may be country level geographical variations in the employment rates of people with first episode psychosis. In the SOHO study, the employment rate in people presenting with schizophrenia to outpatients for the first time in ten European countries is reported to be 33.7% (Novick et al 2007). In comparison, analysing data collected during the same time period in the year 2001 from people presenting with first psychotic episodes in Singapore, Sim and colleagues (2006) describe the employment rate as 57.4%. A particularly high employment rate of 65% is reported for incident cases of schizophrenia in Trinidad also (Bhugra et al 2000).

Where follow-up data are reported in studies, a substantial fall in employment rate has often taken place. In an examination of the 12 month course of people with a first episode of psychosis between 1984-1986 in West Birmingham UK (Birchwood et al 1992), the baseline employment rate of 52% dropped to 25% after 1 year. A study based in Harrow London (Johnstone et

al 1986, Johnstone et al 1990) also reports a high initial employment rate with a fall from 65% to 49% at 2 years.

2.4.5 Is there a relationship between variations over time in the employment rate among people with schizophrenia and among the general population?

2.4.5.1 Methods of comparison

Social recovery in schizophrenia, of which occupational recovery is an important part, may be affected by the macro-economic situation in a country (Warner 2004). The effects of the state of the economy on the employment rate in the general population may differ from the effects in schizophrenia. The ideal way to explore this relationship fully would be to use employment data from a prospective long-term study, which annually sampled a large number of people with schizophrenia over many years, from the same location using consistent procedures and then comparing the rates with that of the general population. Data from such a study are not available and are unlikely to become so in the foreseeable future.

An alternative and pragmatic approach is to use employment data from multiple different studies based in the same country, over a long period of time and to compare this with general population employment over the same interval. This has been done in Figure 1 using UK data to examine possible trends in employment rates in a developed high-income country. In Figure 1 each of the U.K studies in Table 1 is plotted against the year of data collection. The employment rate in the general population (Department for Education and Skills 2001) in the year of data collection is also charted on the graph for comparison. A linear trend line is plotted using the function in Microsoft Word Charts. This creates a best fit straight line through the points. Before the results are discussed the limitations of this type of comparison require consideration.

Figure 1: Employment in the UK general population compared with UK employment in people with schizophrenia over 50 years.

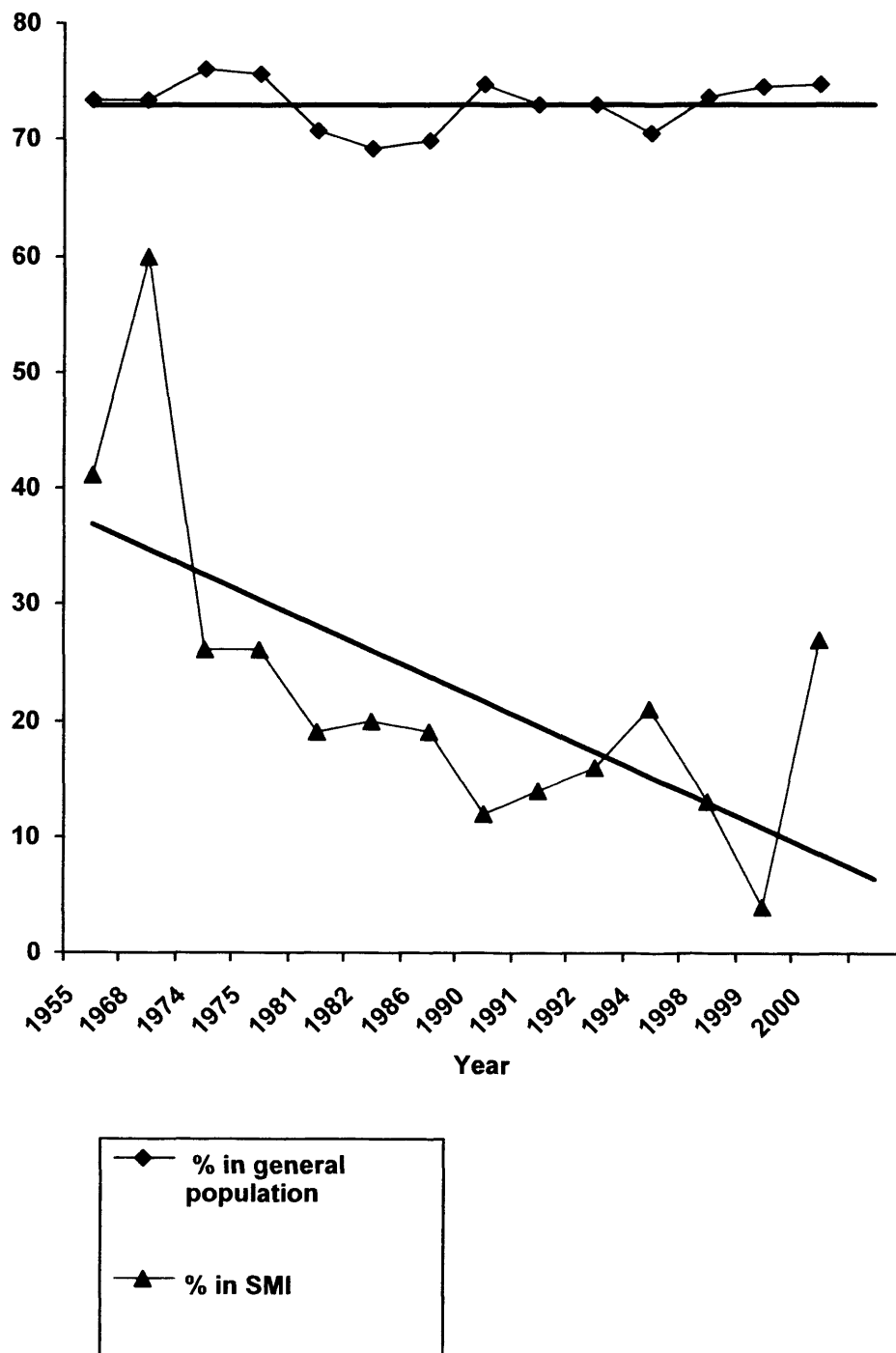
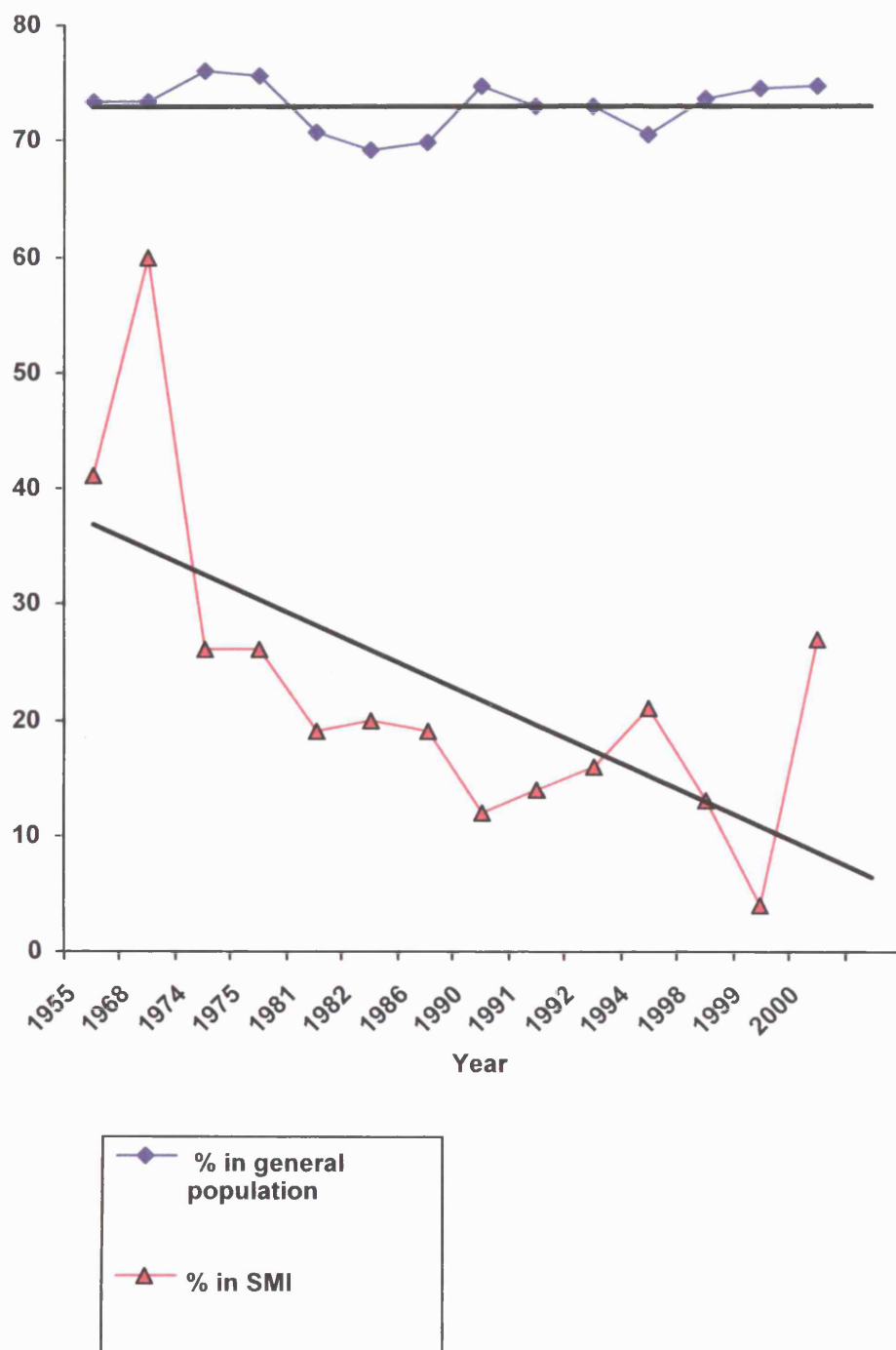


Figure 1: Employment in the UK general population compared with UK employment in people with schizophrenia over 50 years.



2.4.5.2 Limitations of the method used

The employment rates of the UK studies plotted have a range of different sampling methodologies, with some studies recruiting solely at the point of discharge from hospital whilst others use psychiatric or general practice registers or exhaustive inclusion to recruit from the total community. The disparity in the methods of sampling means that interpretation of apparent trends needs to be cautious. Also the studies plotted in figure 1 took place in a number of geographical areas and the rates of employment may have been influenced by local labour market conditions specific to the study site.

The second study plotted on the line, a 1968 study, is an outlier and probably influences the direction of the line to a significant degree. Furthermore, the method of calculating the employment rate in the general population in the UK has changed a number of times over the last 50 years. Finally although Figure 1 shows the total rate of employment in the general population for comparison, the employment rate has decreased overall for men and increased for women over this period.

2.4.5.3. The trend over time in employment levels in people with schizophrenia living in the UK.

Despite these cautions the trend lines shown in Figure 1 suggest that in the U.K the employment rate in those with schizophrenia may have been slowly dropping, whilst the rate in the general population has varied less over a period of about 50 years up to 2000. There are a number of possible reasons for this apparent decline. At the start of the deinstitutionalisation movement there was much more emphasis by psychiatric services on the occupational needs of patients. Industrial Therapy Units, which comprised workshops and factories were set up in most mental asylums in Britain and were seen as one of the key strategies (Anonymous 1969) in the preparation of long stay patients for discharge. In fact male patients were not usually discharged unless they had paid employment, partly because it would be difficult for them to support themselves otherwise.

Work was so valued as a rehabilitative option that in a national survey (Wansbrough and Miles 1968) of people in hospitals, 46% of male and 56% of female inpatients were working. This was either in industrial therapy units, domestic duties or "other types of work traditional in mental hospitals". There is little comparable provision in modern mental health services in the UK. Despite the high rates of employment, the nature of work that was being carried out by people with schizophrenia (Anonymous 1969) was primarily "manual, repetitive and monotonous and often on assembly lines". Moreover, pay was low with a statutory maximum of £2 a week for people in the industrial therapy units. Full-time sheltered work attracting very low rates of pay would now not be possible or acceptable, given the minimum wage and discrimination legislation in the UK.

Labour market conditions have also changed over a number of decades. In the U.K during the early 1960's, demand for manual workers earning relatively low pay was high and the government encouraged immigration (Deaken 1970) from around the world to fill these vacancies. It is possible that in such a labour market those with schizophrenia were much more likely to get work and this may partly explain the high rates during this period. However, since the 1980s, the unemployment rate in the UK in the general population has gradually fallen, while it appears to have risen in people with schizophrenia.

Over time the nature of the labour market has changed with an increasing emphasis on productivity and the dominance of service industries and technology (Lindsay 2003). In this type of market environment, job prospects for those with schizophrenia are likely to be low if they have a poor work history and problems with social skills. People with schizophrenia have also been found to favour work with low levels of interpersonal interaction (Muntaner et al 1993), and this may now be less readily available. It is also possible that the service user movement and deinstitutionalisation may have, understandably resulted in rising expectations among people with schizophrenia so that they are no longer as willing to do the unskilled jobs that the institutionalised were doing in large mental asylums or expected to do on discharge. A post-modern shift in the attitudes of people towards life is noted

in the recent sociological literature (Inglehart 2004). It is suggested that this shift puts a greater emphasis on self expression and quality of life and not hard work and survival. This change in societies attitudes may be relevant in explaining what work people with schizophrenia are willing to do and overall how important it is to them to work at all.

The financial incentives for people with schizophrenia to work are also likely to be part of the explanation for the possible declining employment rate in the U.K. A more generous benefit system in recent times compared to the 1950s and 1960s (Blakemore 1998, Glennerster 2000) may mean that the economic choices of people with schizophrenia are weighted towards persisting unemployment because of the earnings disregard (the amount of income a disabled worker may earn before welfare benefits are reduced). The “benefits trap” is even more potent for those with SMI than for the general population and particularly so for people who want part-time work (Turton 2001). This is because additional disability payments result in a higher income that needs to be compensated for by a salary.

2.4.6 What factors are associated with having a job in people with schizophrenia?

2.4.6.1 General Labour Market Conditions

The general population employment rate is a measure of local and national economic conditions and these might reasonably be expected to affect the job prospects of people out of work. The evidence however that national economic conditions affect employment levels in the severely mentally ill is mixed.

Richard Warner reviewed over 100 epidemiological 20th century studies of recovery from schizophrenia and examined whether there was a relationship between recovery rates and national economic conditions (Warner 2004). He argues that there is a statistically significant correlation between complete and social recovery in people with schizophrenia and average national

unemployment rates between 1901-1995 in developed countries. Thus he suggests that higher employment rates in the general population are linked to better social recovery including higher employment levels in patients with schizophrenia. He persuasively points out that during the Great Depression of the late 1920's and 1930's the rate of social recovery fell as it did during the recession of the 1980's and that a labour shortage in post war Britain was associated with higher recovery rates. He argues that differences in diagnosis or patient selection do not account for the findings. Possible explanations of this historically based link are greater rehabilitative efforts and more demand for the labour of impaired people (Loebel et al 1992) when employment rates in the general population are high.

Research that examines local labour market conditions and employment in people with schizophrenia in the same study is limited and offers no real consensus. Cook and colleagues (2006) tested this potential association using hierarchical random regression modelling of employment data in the context of a RCT of supported employment programmes at 7 sites in the USA. The sample was diagnostically heterogeneous and consisted of 1273 people with Schizophrenia, Major Depression, Bipolar Affective Disorder or Schizo-Affective disorder. They found that over a 24 month period, people in areas with a higher local unemployment rate were less likely to be in competitive employment or working for more than 40 hours / month. This association persisted even when type of intervention and clinical and socio-demographic characteristics of the participants were controlled for.

The results of an elegant sub-analysis of the same data by Cook and colleagues suggests that the type of intervention was however more powerful than local unemployment rates when predicting employment outcomes. Thus over the 24 months of follow-up people in the supported employment group who lived in an area of low unemployment had better outcomes than all other groups. Those in the supported employment group and living in areas of high unemployment did better than those receiving standard care and by the end of the period of follow up there was a trend for people receiving standard care but who lived in low unemployment rate areas to have higher rates of

employment than those receiving the same care but living in an area with high local unemployment.

A number of other studies however have not replicated the association between general population employment rate and the rate in people with schizophrenia. Using the baseline data available from a large multi-site RCT of anti-psychotics, Rosenheck et al (2006) controlled for a wide range of potential confounders and found local employment levels did not appear to have an effect on the occupational status of those with schizophrenia. Summarizing the results from a number of RCTs, the architects of the IPS model of supported employment suggest that a substantial association between wider economic conditions and the employment of the severely mentally ill is lacking (Bond et al 2001a). One of the studies on which this summary is based was particularly methodologically robust and used weekly employment data from the general population and those in supported employment programmes over a three-year period and found no relationship between them (Catalano et al 1999).

The only naturalistic study to date, that has investigated the influence of the local labour market on the employment of people with schizophrenia is the US Schizophrenia Care and Assessment Program (US SCAP) study. This 3 year multi-site evaluation of a large number of people with schizophrenia related disorders (N=2326) also found that regional employment rate did not have any effect on the employment rate of people with schizophrenia (Salkever 2007).

There are a number of possible explanations for why an association may not have been found in some analyses despite the robust epidemiological data presented by Warner (2004). Nearly all of the studies directly testing a potential relationship between the local labour market and employment amongst people with schizophrenia are RCTs of supported employment programmes. Samples in these RCTs are generally unrepresentative of the full range of people with schizophrenia living in the community. By definition those included in the RCTs are usually all unemployed, interested and motivated to get work and willing to enter an intervention study. These criteria

may identify people who would generally be expected to have better outcomes. Thus their better prospects of getting work, especially if they are given considerable help by employment services may mean that they are less influenced by local labour market conditions than one might expect. Also of course the employment rate may rise independently of any effect from local labour conditions if the intervention has any success at all.

Another potential explanation for the absence of an effect of the local labour market can be drawn from an economic theory called the dual-labour-market model (Fine 1987). The theory holds that regional economies are made up of the primary and secondary labour market. The former category is made up of occupations, which involve significant commitments by employers and workers over an extended period of time and infer expensive benefits to the employees. The secondary labour market is characterized by much more part-time, temporary and low paid work. It is jobs in the latter sector that most people with schizophrenia tend to work in (Bond et al 2001a). The theory suggests that in times of recession jobs are lost in the primary labour market, but the secondary market that generally includes entry-level jobs is more elastic and less vulnerable to this change. Although speculative, people with schizophrenia may be protected to some extent from a down turn in the economy precisely because of the nature of the work they tend to do.

Finally all the studies described above use local employment rates as a proxy indicator of local labour market conditions. Although statistically satisfactory the local employment rate is unlikely to fully explain local job availability, the level of black market employment, the extent of competition for jobs, the skill mix of the population and variations in the nature of the work on offer.

2.4.6.2 Demographic variables associated with having a job

As in the investigations reporting employment rates, a variety of different study types were retrieved by the search strategy. Methodologies and the candidate variables tested for their association with working varied from study to study,

and samples were often small. The outcome variable work was defined in a number of different ways also.

Despite these difficulties, Wewiorski and Fabian (2004) completed separate meta-analyses for the associations with employment of age, race and gender in the severely mentally ill, though they note the caveats described above. Also they acknowledge that their findings were vulnerable to change if an additional study were to be reported given that the number of studies in one of the meta-analyses was as small as only two. No effect was found for gender but age and race were associated with work status although the size of the effect was small.

The findings from the current literature review on the possible associations with employment of a range of demographic variables are discussed below. Table 4 summarises studies that tested the link between current work status and at least 2 of the following: age; gender; education; ethnicity and work history.

2.4.6.3 Gender

The nature of the relationship between gender and working is unclear as a number of well conducted studies using a range of different methodologies appear to report divergent results. Many older studies (Fabian 1992, Arns and Linney 1995, Mowbray et al 1995) report no link although most are evaluations of vocational services in the USA and tend to have small sample sizes.

Table 4: Summary of main demographic factors that may be associated with working

Author (s)	Study type	Age	Education	Ethnicity	Work history	Gender
Pandiani et al 2004	Cross sectional N=2,938	Younger age: ↑ emp	Not tested	Not tested	Not tested	Male: ↑emp
Burke Miller et al 2006	RCT N=1,273	Older age: ↓ emp	Less than high school education: ↓ emp	Caucasian: ↑ emp	Any work in last 5 years: ↑emp	Male: ↑emp
Salkever et al 2007	Prospective naturalistic N=2,326	Older age: ↓ emp	More years of education: ↑ emp	Hispanic: ↓emp African: no effect	Not tested	Male: ↑emp
Mubarek 2006	Cross sectional N=200	Not tested	Not tested	Not tested	Not tested	Male: ↑emp
Rosenheck et al 2006	RCT N=1,438	Not significant	Higher school or greater: ↑emp	Black: ↓emp	Not tested	Not significant
Mowbray et al 1995	Cross sectional N=277	Not significant	Not tested	Not significant	Not tested	Not significant

Author (s)	Study type	Age	Education	Ethnicity	Work history	Gender
Arns and Linney 1995	Psycho-social rehabilitation programmes N=138	Not significant	More education (undefined): ↑emp	Not significant	Better work history ↑emp	Not significant
Honkonen et al 2007	Hospital discharges N=2168	Not significant	Not tested	Not tested	Not tested	Not significant
Rogers et al 1991	Entry into vocational rehabilitation programme N=275	Not tested	Not significant	Not tested	Not tested	Not significant
Mechanic et al 2002	Household survey N= 320	Younger age: ↑emp	Not significant	Not significant	Not tested	Not significant
Fabian 1992	Follow-up of vocational placements N= 90	Not significant	Not tested	Not significant	Not significant	Not significant
Miettunen et al 2007	Follow-up study N= 113	Not tested	Not significant	Not tested	Not tested	Female: ↓emp

In a number of observational studies, female gender is associated with a more positive employment outcome. Thus in the Nithsdale schizophrenia surveys (McCreadie 1982), a cohort study in a geographically defined area in Scotland, males were less likely to be employed. An association between female gender and employment has also been replicated in other follow-up studies in the USA (Beiser et al 1994), Nottingham, UK (Harrison et al 1996) and using data from the Danish Psychiatric case register of over 5000 people with schizophrenia matched with 50000 controls (Agerbo et al 2004).

More recent observational studies and RCTs of supported employment programmes, in which sample sizes are larger, sometimes running into many hundreds, report an increase in the odds of employment for men in comparison to women (Pandiani et al 2004, Burke-Miller et al 2006).

2.4.6.4 Ethnicity

Ethnic background is known to have an important association with employment status. In the general population in the UK (Smith 2002) as well as in the USA (US Department of Labor 2001), Black-African people are less likely to be in employment compared to all other ethnic groups. In people with schizophrenia also, being from a non-white ethnic background lowers the odds of being employed in the US (Rosenheck et al 2006, Fabian 1992) although surprisingly many UK studies do not report a difference (Goldberg et al 2001, McKenzie et al 1995, McKenzie et al 2001), possibly because of the low power of most studies.

2.4.6.5 Age

Younger age has been associated with being employed both in cross-sectional surveys (Mechanic et al 2002, Pandiani et al 2004) as well as in RCTs (Salkever et al 2007). The absence of an association is also apparent in a number of reports (Mowbray et al 1995, Wewiorski and Fabian 2004, Rosenheck 2006, Honkonen et al 2007). The possible connection between younger age and having a job in people with schizophrenia may be explained

by the fact that social disability tends to accumulate with increasing number of episodes (Birchwood et al 2000) and that with this growing impairment mental health professionals help persons gain eligibility to disability benefits (Mashaw and Reno 1997), thereby reducing the likelihood of work being sought. Thus it may be that age of illness onset or length of illness are equally important to age when explaining the likelihood that a person will be employed.

2.4.6.6 Work History

The relationship between past work history and subsequent occupational performance appears to be relatively consistently replicated in both cross sectional and prospective studies (Anthony and Jansen 1984, Arns and Linney 1995, Drake et al 1999, Mueser et al 2001, Russinova 2002) and in two previous reviews of the literature (Wewiorski and Fabian 2004, Tsang et al 2000). It has been suggested that past work performance could account for as much as a quarter to a half of the variance of future employment outcome (Anthony and Jansen 1984, Anthony 1994).

Despite this, in a selective review of individual level predictors of employment outcomes, previous work history was not found to be important (Michon et al 2005). One potential explanation is that the review of Michon et al (2005) only includes evaluations of psychiatric vocational programmes and therefore may be biased towards people who are motivated to find employment. Alternatively it is possible that work history is more important in explaining future occupational outcome if the person finds work unaided by vocational services.

Although it appears that a history of previous employment is important, we do not yet know which aspect of work history is most relevant. What is meant by work history is rarely defined in most studies and when it is, there are differences in the definitions used between analyses. Depending on researcher preference it has been defined as: the number of previous jobs; longest length of employment; number of hours worked; and any paid work over the last 5 years. An additional problem with the diversity in its definition is that it is nearly always unclear if the history of work is pre-morbid or after

illness onset, or whether this distinction is considered to be unimportant. Whether the distinction is relevant is currently unknown, as overall pre-morbid functioning is usually not considered separately from work history in studies examining predictors of future work status.

2.4.6.7 Education

Level of education is a component of pre-morbid functioning that appears to be an important predictor of employment status in people with schizophrenia, similar to its effect in the general population (Miettunen et al 2007, Mechanic et al 2002). In an analysis of factors associated with working in a sample of 169 people with schizophrenia derived from a population based survey in Australia, overall educational level and specifically vocational qualifications and having a diploma or degree were predictive of employment (Waghorn et al 2004). Using 2 year follow-up data from 1273 people with DSM Axis 1 diagnoses living in the USA, Burke-Miller et al (2006) report that, independent of work history, having less than a high school education prospectively predicted competitive employment as well as working at least 40 hours a month. The fact that onset of schizophrenia is often during a person's normal years of education means the loss of opportunity to obtain qualifications may be particularly damaging to future employment prospects. Having a higher level of education appears to predict having a job whether this is transitional, open market or in sheltered settings (Michon et al 2005) but may be most robustly associated with competitive employment (Rosenheck et al 2006, Hofer et al 2005).

2.4.6.8 The relationship between work history, education, pre-morbid functioning and employment status

Although it is likely that previous work history and educational level are predictive of future work their connection with and independence from overall pre-morbid functioning requires further exploration. Both work history and education have been correlated with pre-morbid functioning in a longitudinal study of work (Mueser et al 2001). Furthermore pre-morbid functioning was

found to strongly predict occupational status at 5 year follow-up in the Washington cohort of the WHO International Pilot Study of Schizophrenia (Strauss and Carpenter 1974) and at 25 year follow-up of a schizophrenia cohort in Denmark (Agerbo et al 2004). Although such associations are not universally found (Harrison et al 1996), clear conclusions cannot be drawn from the available literature as to whether degree of general pre-morbid social functioning may in fact be as good as, or better than work history or education level in predicting future employment.

2.4.6.9 Marital status, accommodation and area of residence

Other demographic factors associated with working in some studies include marital and accommodation status and rural environment. Factors related to better social outcome were analysed in a multi-site 3 year follow-up of 275 patients (Rogers et al 1991, 1997) entering vocational rehabilitation in Boston. Although no differences were found in gender or in educational and residential status between those who worked and those who didn't, being married was associated with having a job. In an investigation of the predictors of occupational status of 113 people with schizophrenia from the Northern Finland 1966 birth cohort, being married or cohabiting at onset independently increased the odds of not being on any pension (a marker of occupational functioning in this study), even when work adjustment and good pre-morbid social adjustment were controlled for (Miettunen et al 2007). The association between being married or cohabiting and employment has also been found in Australia (Evert et al 2003) and in another study based in Finland (Honkonen et al 2007). It is possible that the association between being married and having a better prognosis generally (Srinivasan & Thara 1997) confounds the link between marital status and employment.

Other factors such as residential status and degree of urbanisation of area of residence may also be important in explaining work status, but have only been investigated in a limited number of studies. In the First National Survey of Psychiatric Morbidity in Great Britain (Foster et al 1996), owning one's own property was strongly associated with employment, although the causal

direction is unknown. In the assessment of regional variations in competitive employment among people with SMI in New Hampshire, US (Drake et al 1998), rural centres tended to have higher rates of employment.

2.4.6.10 Psychotic Symptoms

The severity of psychotic symptoms has been moderately correlated with a range of different social outcomes including social skills (Bellack et al 1990), frequency of social contacts (Lysaker and Davis 2004) and the ability to live independently (Sayers et al 1996). Numerous studies have investigated the relationship between psychotic symptom severity and employment status also, but there is only limited agreement on whether they are connected.

Most studies retrieved by this literature search evaluate the correlation with working of positive or negative psychotic symptom score. There was a tendency for many of the studies found to have diagnostically heterogeneous small samples of around a 100 people or less and they differed in the extent to which they controlled for potential confounders. An additional issue with much of the literature found is disentangling the direction of causality of the correlation between psychotic symptoms and work status. Often it could very plausibly be in either direction.

A previous review (Anthony & Jansen 1984) citing older evidence reported that there was no relationship between psychotic symptoms and functional capacity to work. However, more recently McGurk and Mueser (2004) completed a review of the literature and suggest that there may be an association with at least some types of symptoms. They searched PubMed for published reports dated between 1970-1993 and then augmented this with searches for longitudinal studies aiming to predict outcome. This strategy revealed 27 separate studies.

McGurk and Mueser (2004) did not consider a meta-analysis feasible. Instead they used a “box score” approach to summarise the results by tabling all relevant studies and indicating whether correlations were found between work

and symptom scores. On the basis of a count of positive results (the box score) they conclude that in cross-sectional and retrospective studies overall symptom score as well as positive and negative psychotic symptoms are correlated with a better work outcome. These correlations were less frequently reported in prospective studies, and in those sampling people in vocational rehabilitation services, only negative psychotic symptoms remained important in explaining work status.

One of the weaknesses with the review of McGurk & Mueser (2004) is that no attempt is made to assess the quality of the studies or to weight the results according to sample size. In examining the available literature for the current review, it is striking that the findings of studies with larger samples sizes with regards to the association of work status and positive psychotic symptoms are rather mixed.

For example in an epidemiological survey based in Australia of people with psychosis (N=902) those who were working had lower positive symptom scores (Gureje et al 2002), replicating the results of a large US cross sectional survey (Slade and Salkever 2001). A longer term follow-up study (N=173) also reports a similar association between employment status and positive psychotic symptom levels (Racenstein et al 2002). However an association has also been absent in a number of large and well conducted cross-sectional surveys (Rogers et al 1991, Goldberg et al 2001), as well as in follow-up studies (Mueser et al 2001, Anthony et al 1995). It is also the case that greater severity of positive psychotic symptoms has paradoxically been found to be associated with being employed (McGurk & Meltzer 2000), suggesting that their presence does not preclude working.

It is more probable that the negative symptoms of schizophrenia are associated with unemployment, as the literature is more consistent. This is the case in cross-sectional (Westermeyer and Harrow 1987, Solinski et al 1992, Schulberg et al 1999) and in prospective studies (Johnstone 1991, Lysaker & Bell 1995). Some smaller studies using multiple regression analyses suggest that the association of more severe negative symptoms and unemployment is

independent of and stronger than any effects of positive symptoms (Breier et al 1991, Hoffmann & Kupper 1997). The impact of negative symptoms may be mediated by their effects on interview performance (Solinski et al 1992), task orientation, social skills and personal presentation (Lysaker & Bell 1995), or simply by a lack of motivation to find work.

2.4.6.11 Social Behaviour, Attitudes and Skills

Social functioning appears to influence the likelihood that a person with schizophrenia will be employed. In a retrospective analysis of 156 patients (primarily long stay schizophrenia patients) who were discharged from hospital, those who were working had low levels of social withdrawal and socially embarrassing behaviour (Morgan & Gopaldaswamy 1983), though social withdrawal may be an indicator of negative symptom severity. The jobs held by people with schizophrenia were found in this study to require relatively little interpersonal interaction, a finding also replicated in a case control study of veterans with psychosis (Bacani-Oropilla et al 1991). Thus some people with schizophrenia may seek out jobs in which their style of and capacity for social interaction with others is not a hindrance or can be accommodated.

Data from the study of Low Prevalence Disorders in Brisbane (Evert et al 2003) relating the functioning and social networks of 908 individuals (most with a diagnosis of schizophrenia) revealed a strong association between social integration and functioning defined as being employed ($r = 0.71$), even after controlling for illness course. Good social skills in people with schizophrenia have been associated with employment in a number of other studies (Cook and Razzano 2000). Thus poorer interpersonal skills may influence interview performance and subsequent functioning at work if a job is obtained. Poor social functioning may relate to the effects of the illness, but also to intrinsic personality factors such as high extraversion or neuroticism scores, which have been correlated with poorer work functioning (Lysaker et al 1998).

The attitudes of people with schizophrenia and their resultant job-seeking behaviour have not been extensively studied, but in the general population it is evident that those actively looking for a job are more likely to obtain work in the future than those who are not (Tano 1991). In a large (N=528) prospective analysis of work in people with schizophrenia (Mueser et al 2001), the desire to work at baseline was associated with future employment at 1 and 2 years follow-up. Similarly a “positive attitude to work” was predictive of employment in participants of an assertive community treatment and rehabilitation programme (Mowbray et al 1995).

As well as a desire to work, work adjustment skills such as punctuality and communication and listening skills as assessed in a sheltered job site, are thought to be important in predicting future employment (Cook and Razzano 2000, Hoffmann et al 2003). It also possible that functional skills in other domains such as, social interaction, personal hygiene and handling finances (Arns & Linney 1995) may be related to work performance.

2.4.6.12 Cognitive symptoms

Over the last ten years a burgeoning literature on the effects of cognitive problems in people with schizophrenia and functional outcomes is evident. The vast majority of people with schizophrenia have some element of cognitive dysfunction (Gold and Harvey 1993, Green et al 2000). This precedes role impairment (Häfner et al 2003) and does not tend to improve when people with SMI get work (McGurk and Mueser 2003). In reviewing the literature for this thesis there was a wide variation amongst studies on the neuro-cognitive measures tested and employment was usually one of a number of outcomes that was used to assess the impact of cognitive problems.

There is consistent evidence, albeit from small studies, that difficulty in cognitive processing is related to poorer work functioning. This effect has been found both cross-sectionally and in long-term follow-up studies whether the participants are sampled from outpatients or supported employment

service programmes (Gold et al 2002, Evans et al 2004, Hofer et al 2005, McGurk and Mueser 2006). For example, in analysis of covariance (ANCOVA) testing of data sampled from people entering a vocational programme (N=38) (McGurk & Meltzer 2000), those who were employed full-time did significantly better on tests of working memory, vigilance and executive functioning than those who were unemployed. This relationship persisted even after education was controlled for.

Cognitive difficulties are predictive of future unemployment in people with recent onset schizophrenia also. In a prospective multi-centre Dutch study sampling people who had been diagnosed with schizophrenia within the last 2 years the risk of work related impairments was almost twice as large for people with cognitive impairments at inclusion as for those without substantial cognitive problems (Holthausen et al 2007).

In reviewing the literature on cognitive deficits and a variety of outcome measures including those that are community based such as employment, Green et al (2000) suggest that specific deficits are likely to be associated with work functioning. Thus they report that difficulties in secondary verbal memory, verbal fluency and card sorting (a measure of cognitive flexibility in the face of a changing situation) are specifically associated with unemployment. All these types of deficits are likely to interfere with interpersonal skills, communication and task completion.

Disturbances in cognitive processing may underlie the problems of social integration, functional skills and negative symptoms that affect work performance. Many studies (Green 1996) report that the cognitive deficits found in schizophrenia are associated with poor social skills functioning and problem solving, so that there is a potential pathway linking these deficits to unemployment. Indeed, there is evidence that problems in contextual processing are related both to symptoms and employment (Allen 1990).

2.4.7 Is there evidence that being employed may influence other outcomes in schizophrenia?

Given that people with schizophrenia say they want to work, and that increased resources are likely to be needed for mental health services actively to facilitate this, it is important to know whether employment can influence other outcomes.

In reviewing the literature in this area two different study designs were frequently found; firstly there were correlational analyses of employment and other outcomes largely from epidemiological follow-up studies and secondly experimental trials of vocational services in which the relationship between employment and other outcomes had been examined.

There was a significant degree of inconsistency in the results of the limited number of studies that were retrieved by the literature search. It is difficult therefore to form a robust view on whether employment does affect other outcomes. Even in the studies reporting positive results there is the major problem of being confident of the direction of causality. Thus it is difficult to know whether people get a job because they get better in a variety of other domains or vice versa.

2.4.7.1 Evidence from cross-sectional and longitudinal data

Moderate correlations have been found between employment and other social outcomes as well as psychotic symptoms in long-term follow-up studies, although few have controlled for important baseline factors such as previous work history. For example, Strauss and Carpenter (1977) reported that there were correlations between outcome measures such as social contacts, employment and psychotic symptoms, with each explaining between 17% and 36% of the other's variance. In the Washington IPSS cohort at 11 years (Carpenter & Strauss 1991), hospitalisation, social contacts, employment and psychotic symptom severity were all significantly but only moderately correlated with each other. More recently, the result of a 10-year follow up of

173 people with SMI demonstrated that regardless of diagnosis, greater severity of psychotic symptoms was associated with a reduced likelihood of working at each of four successive follow-up assessments (Racenstein et al 2002).

Some of the most consistent evidence that employment can affect other outcomes comes from a number of studies that report that working is associated with a better quality of life (Arns and Linney 1995, Van Dongen 1996, Priebe et al 1998, Eklund et al 2001). Supporting this association is the finding that losing a job has been correlated with a subsequent lowering of quality of life. Thus in a 1 year follow-up study of people presenting with their first episode of psychosis, participants who became or continued to be unemployed at 1 year had significantly lower quality of life scores than those who maintained employment or student status (Addington et al 2003).

We are only beginning to explain the possible underlying mechanisms of any association between working and better quality of life. Self-esteem, for example may mediate the link, as it has been correlated with both (Brekke et al 1993, Van Dongen 1998). Having a job may improve access to social contact and Ruesch et al (2004) suggest that a larger number of social ties in those who are working may explain the relationship between quality of life and work.

2.4.7.2 Evidence from experimental trials

Many early experimental studies evaluating the effectiveness of the IPS model of supported employment, which demonstrated increased employment rates in the intervention arm, fail to show substantial changes in the non-vocational outcomes of participants (Drake et al 1999a). In the context of this review the main limitation of much of the evidence from these earlier studies is that the analyses were designed to investigate the effect of a vocational intervention on other outcomes as opposed to the effect of work per se. Thus it was the type of intervention that was used as the independent variable in analyses as opposed specifically to the numbers working.

More recently in the Hartford Study of supported employment (Mueser et al 2004) over 200 people with SMI were randomized into 3 different treatment arms, all of which were effective in improving employment rates by the 2-year follow-up point. Global assessment scale (GAS) scores of the participants tended to improve over time but no effect was found for psychotic symptoms, social functioning, social networks, self-esteem or quality of life.

In a secondary analysis using mixed effects regression modelling of the data from a randomized study of supported employment conducted in Washington (N=149), statistically significant differences were found in a number of different outcomes between those who were working and those unemployed (Bond et al 2001b). Thus the competitively employed group were more satisfied with their finances and leisure activities and had higher self esteem compared to those in the minimal working / no work group at study end. Working was also associated with a significant improvement in total Brief Psychiatric Rating Scale (BPRS) score as well as on the Affect and Disorganization subscales. Interestingly the net difference in BPRS score over the 18 months for workers who had received IPS was not large (a 2 point drop), but all other groups experienced a worsening of symptoms, possibly suggesting that having a job was somehow protective.

Mueser and colleagues (1997) explored the question of whether clinical benefits are apparent if baseline factors are controlled for. Non-vocational aspects of the functioning of 143 unemployed people with SMI participating in an 18-month study of vocational rehabilitation programmes were assessed every 6 months. Patients who were working at follow-up had less severe symptoms (particularly thought disorder and affect), higher GAS scores, better self-esteem, and more satisfaction with their finances than unemployed patients even after controlling for baseline factors.

Evaluations of other types of vocational intervention have also indicated the potential of work to influence psychotic symptoms and hospitalisation, but again it is not possible to make confident generalizations because of study

methodologies. In a randomised trial of 150 people with SMI who were assigned to a pay or non-pay group and given a 6 month work placement, those who had been paid were working more hours. They also showed a statistically significant improvement on symptoms and had lower re-hospitalisation rates, and these clinical benefits were maintained at 1 year follow up (Bell et al 1996, Bell & Lysaker 1997). The sample however consisted almost entirely of male veterans with very long psychiatric histories and the study was organized to investigate the effects of paying people for work as opposed to whether working per se is linked to other outcomes. In a small (N=83) German 3 year follow-up study investigating the effects of “work therapy”, those with a better rehabilitation course had significantly lower re-hospitalisation rates, but work had no direct effect on psychopathology (Reker & Eikelmann 1997).

Evidence from an experimental trial adds weight to cross sectional and longitudinal studies suggesting employment improves quality of life. Bond et al (2001b) suggest whether or not the job obtained by a person is of the open market type appears to influence whether quality of life improves. Thus in their study people in competitive employment had a higher quality of life than those who were not working, but this improvement did not hold true for people employed in sheltered settings.

2.4.8 What are the barriers to employment that people with schizophrenia face?

The main barriers to employment for people with schizophrenia described in the literature are stigmatisation of the mentally ill, economic disincentives, the attitudes and self-esteem of patients themselves, and the response of mental health services to their needs for support in obtaining and maintaining work. Many of these factors are similar to the barriers faced by the long-term unemployed (Blumenberg 2002), but those with schizophrenia face the added burden of their illness.

2.4.8.1 Stigma and discrimination

People with schizophrenia commonly report that stigma is one of the biggest factors preventing them from obtaining and keeping work. In a qualitative study (Schulze & Angermeyer 2003) sampling people with schizophrenia, relatives, and mental health professionals from German out-patient centres, all reported that the stigma of schizophrenia was a major barrier to employment. Specifically they identified four dimensions of stigma that affected the ability of patients to work. These were adverse effects on interpersonal interactions, structural discrimination (disproportionately less expenditure on mental health services), public images of mental illness, and a lack of access to valued social roles. Study participants reported that public images were responsible for a “hostile social climate” towards people with schizophrenia and that this was central to their diagnosis denying them access to the labour market. Also they suggested that after treatment for an episode of illness a return to work was often accompanied by criticism and a denial of their skills by employers.

There is evidence albeit from a single study, that the judgements of people with SMI about how employers view them are consistent with the actual attitudes of business personnel. In a questionnaire survey of two hundred directors of large businesses, half said they would never or only occasionally employ someone who was currently unwell. This figure dropped to 28% when they were asked about people who had previously been mentally ill (Manning & White 1995). Compared to those with other illnesses, respondents said they were much more likely to dismiss people with schizophrenia if they became unwell whilst in post. Interestingly larger businesses were significantly more likely to offer work to someone with mental illness, possibly because they tend to have occupational health departments who can advise them. Another potential reason is that compared to small businesses there may be a greater capacity in larger companies to cover the work load of those who become ill.

2.4.8.2 Loss of welfare benefits

A number of surveys report the loss, or feared loss of benefits as a powerful barrier to working for people with schizophrenia (McQuilken et al 2003, Rinaldi & Hill 2000, Noble 1998). For example, in interviews with service users regarding their employment needs, 70% of those who were not interested in working said that worries over benefits were important in their reasoning (Secker et al 2001).

However studies reporting concern over benefit loss as a barrier to employment, frequently do not explore whether these beliefs are founded on actual experiences within the welfare system of participants or on their fears. Economic disincentives to working such as the benefits trap are inherent in the social policy of many countries, but differently set earnings thresholds that lead to withdrawal of state benefits may affect the decision of people to work. Countries such as Italy in which there is a higher earnings disregard tend to have a higher level of employment among people with schizophrenia (Warner 2001).

2.4.8.3 Individual factors

Surveys of people with mental illness suggest that they wish to work, but service users interviewed by McQuilken et al (2003) expressed open doubts about employment. Participants reported concerns about receiving low pay and being ashamed of their own employment history. Some people also believe that they will not be able to cope with work (Garske & Stewart 1999). Similar to these results are the findings of a study of ten young people with first onset psychosis in Australia (Bassett et al 2001). Major impediments to job-hunting were losses associated with illness, low self-confidence and self-esteem.

It is likely that self-confidence and the attitudes that service users have about work will affect their chances of getting work and keeping it. The beliefs of clients of an Assertive Community Treatment programme who were able to

obtain and sustain employment were found to be different from those who were unsuccessful at doing so (Cunningham et al 2000). People in employment tended to be able to see their illness as just one part of who they were. Those who were unemployed tended to either deny their illness or to define themselves by it. In addition respondents who were out of work usually described illness management strategies involving covering up their illness or pushing it aside when making decisions about work.

2.4.8.4 Staff attitudes

Many authors suggest that mental health professionals may unintentionally collude with the barriers that people with schizophrenia face in gaining work (Bond 2001a, Grove and Membrey 2005, Royal College of Psychiatrists UK 2002), although substantial evidence from adequately sized research studies showing this to be the case is actually rather scarce.

A number of factors may underlie these assumed attitudes. Firstly they may merely represent the knowledge and real experience of mental health professionals with regards to the mentally ill working. In a qualitative study conducted in Turkey, for example, clinical hospital personnel were more negative about the prognostic outcomes of people with mental illness when compared to the opinions given by non-clinicians at the hospital (Aydin et al 2003).

The attitudes of staff may also suggest that to some extent they wish to protect patients against the stresses of work, fearing that there may be a detrimental effect on mental health. This appeared to be the case in an investigation of the employment of service users in an assertive outreach team in South London. Staff were concerned that employed patients were not well enough to work and would take a disproportionate amount of sick leave (Doherty et al 2004), beliefs which have been expressed by staff in other service user employment programmes (Perkins et al 1997). There is also concern by mental health professionals that working may cause relapse

(Vogel et al 1989) and this view is consistent with concerns that patients may themselves have.

It is suggested that even staff charged specifically with vocational rehabilitation place their patients in low wage jobs, regardless of the person's previous job experience, based on the concern that the stress of more challenging work will exacerbate symptoms and cause a deterioration in mental health (Goldberg et al 2005). It has been suggested that mental health professionals may advise people with SMI not to work (Rinaldi and Hill 2000) or not offer them vocational services (Lehman et al 1998) reflecting either low expectations among professionals, a lack of resources or an inconsistency between the priorities set by professionals and service users (Crane-Ross et al 2000).

2.5 Summary

Although a fuller discussion of the results of the literature review is presented in Chapter 8, the main findings are described here. Employment rates in people with schizophrenia are very low, though there may be significant country level differences. Those experiencing first episodes tend to have higher rates compared to people with established schizophrenia. Whilst it is difficult to be sure, it does appear that the employment rate in people with schizophrenia in the UK may have been falling gradually over the last 50 years. Though the strongest evidence is for work history, negative psychotic symptoms and cognitive deficits, age, gender and education level may also be associated with employment status. Evidence from epidemiological studies as well as experimental trials suggests that employment may influence outcomes such as psychotic symptoms, hospitalisation rates, general functioning and subjective quality of life though the evidence base is not strong. Barriers to working for people with schizophrenia are stigma and discrimination, the benefits trap and individual factors such as low confidence and doubts about a return to work. A number of authors also suggest that staff attitudes are a significant hindrance.

Chapter 3

The rates and correlates of employment in people with schizophrenia in the U.K, France and Germany: an analysis of the baseline data from the European Schizophrenia Cohort (EuroSC) study.

3.1 Introduction

Most studies examining the rate of employment and the correlates of working in people with schizophrenia have small sample sizes or have recruited from specialist vocational services, raising the possibility of significant biases as discussed in Chapter 2. These methodological difficulties may in part explain some of the inconsistencies in the current literature. Very little has been written about the types of work people with schizophrenia do. The analyses in this chapter cover Aim 2 and part of Aim 3 of this thesis and to some extent respond to a number of the problems with the current literature as outlined. Large international naturalistic comparative investigations of employment are rare and the analysis in this chapter represents one of only two as far as I am aware. It also provides an opportunity to examine the possible impact of country level differences in service provision and social environment on the rates of employment in people with schizophrenia.

3.2 Aims

- To examine the rates and employment patterns of a representative sample of people with schizophrenia living in the UK, France and Germany.
- To analyse cross-sectional data to describe the correlates of working.

3.3 Method

The analyses in this chapter as well as those in Chapters 4 and 5 use as their basis the dataset from the European Schizophrenia Cohort (EuroSC) study, a naturalistic 2 year follow-up of people aged 18-64 years suffering from schizophrenia and in contact with secondary psychiatric services in the UK, France and Germany. Data collection started in 1998 and was completed in 2001. Bebbington et al (2005) provide a complete description of the study methodology, but a thorough explanation as it relates to the analyses completed for this thesis is provided here.

3.3.1 Description of study centres

3.3.1.1 France

A law defining 800 catchment areas drives mental health care in France. Each catchment area has around 70,000 people living in it. Within these geographical areas care is provided by a public health maintenance organisation called a 'sector' (Kovess et al 1995). The sector provides inpatient as well as outpatient care.

The strategy for the study was to integrate ten adjacent sectors into a single sampling area and three such integrated areas were identified. They were located in northern France (Lille), central France (Lyon and Clermont-Ferrand), and southern France (Marseille and Toulon). Each of these areas covers an urban centre of approximately 1 million inhabitants living in a city or in medium-size towns. These centres are referred to hereafter as Lille, Lyon and Marseille.

3.3.1.2 Germany

In Germany the Länder (regions) are responsible for implementing federal laws in the planning of mental health service systems. Despite the unification

of Germany, there are still some differences in the health care system between the former West and East Germany (Bauer et al 2001). The mental health systems do not ensure continuity of care. Patients are free to consult any doctor or team at any time and they may be transferred between different medical teams with no co-ordination between the services.

The study in Germany was carried out in four catchment areas: Leipzig and nearby Altenburg in former East Germany, and Hemer and the County of Heilbronn in former West Germany. In the former East Germany the study site covered the city of Leipzig, which has about 490,000 inhabitants and the city and county of Altenburg, which together have about 120,000 inhabitants living in villages and medium-size towns. Data from these two areas were pooled, and are referred to subsequently as the Leipzig centre.

The Hemer site is located in North Rhine-Westphalia on the outskirts of the Ruhr conurbation. It covers the cities of Hemer, Iserlohn and Werdohl, which together have approximately 160,000 inhabitants. The city of Eppingen is located in Baden Württemberg in the southwest of Germany. It has about 90,000 inhabitants, and the study site covered the city and the surrounding county of Heilbronn, which together have about 500,000 inhabitants living in villages and medium-size towns. Data from Eppingen and Heilbronn were pooled and are referred to hereafter as the Heilbronn centre.

3.3.1.3 United Kingdom

In the United Kingdom the government has placed great emphasis on the *Care Programme Approach* (CPA), whereby there is active planning of care between all responsible agencies, with particular emphasis on initiatives at the point of discharge from hospital (Johnson et al 2001). The Care Programme Approach has been widely adopted, although there is still some variation in how it has been implemented.

In the UK, two centres with differing socio-demographic characteristics were purposely chosen to ensure the sample was representative of the full range of

people with schizophrenia. The centres were Islington, a socially deprived inner-city area of London, and a reasonably affluent semi-rural area of Leicestershire. Islington is an inner city London borough with a population of 176,000 (Office of Population Censuses and Surveys (OPCS) 2001). Although there are pockets of considerable affluence, it is one of the ten most deprived areas in England. The county of Leicestershire was chosen excluding the city of Leicester and its suburbs. This area comprised a mix of villages and medium-sized towns with a population of approximately 330,000 persons (OPCS 2001).

3.3.2 Sampling

The participants were selected to provide a representative sample of people with schizophrenia under the care of secondary mental health services. Depending on the organization of the health care system and of patient management, either the strategies of random sampling or exhaustive inclusion were adopted.

Random sampling was used in all the French centres and in Islington, London. In these centres a list of all people with a psychotic diagnosis was established from information already kept by the mental health services and a random sample was taken from those identified. In Islington patients were randomly sampled from the whole local list while in France sampling was stratified so that within each centre 10 patients were randomly selected from each of the 10 local sectors making up an integrated sampling area. In Islington participants were eligible for inclusion if they had been in contact with secondary psychiatric services at any time within the previous four years. Thus in Islington even if people were no longer in contact with secondary services they were approached for inclusion in the study.

Exhaustive inclusion was the basis of sampling in the German centres and in Leicestershire. A list of all potential participants in each catchment area was compiled, again from information already kept by mental health services, and all eligible people were approached for inclusion. In all centres a diagnosis of

schizophrenia was confirmed after an interview using structured instruments by a study investigator who applied the Diagnostic and Statistical manual-version IV (DSM-IV) criteria.

3.3.2.1 Inclusion criteria

Patients who met all of the following criteria were eligible for the study:

- Aged between 18 and 64 years at the time of enrolment in the study
- The participant had a diagnosis of schizophrenia according to DSM IV criteria (American Psychiatric Association (APA), 1994).
- Written informed consent was obtained.

3.3.2.2 Exclusion criteria

Patients who met one or more of the following criteria were not included in the study:

- The participant had been hospitalised for the last 12 months
- The participant was currently roofless, that is living rough on the streets (although other homeless patients could be included)
- The participant was planning to move during the study period in a way that made it impossible to perform the follow-up visits.

The study was observational, as no intervention was made either by or at the behest of the research team. The patients were followed-up for a 2 year period, with data collection at every six months.

3.3.3 Instruments used

Based on individual interviews with the patients, assessments of clinical state and quality of life were made every six months. An extensive battery of instruments was used to collect information at these interviews, but only those relevant to this analysis will be presented here. Full descriptions of the instruments used are given in Appendix B.

Employment data were obtained through the Lehman's Quality of Life Interview (QOLI) (Lehman 1983). The psychometric properties of the QOLI are well established and have been extensively investigated. Construct and predictive validity has been reported to be good using confirmatory factor analyses and multivariate predictor modelling (Lehman 2001). The QOLI establishes whether participants are currently employed and if relevant, their job title. Questions on receipt of welfare benefits are also included. Therefore it is possible to describe the numbers working without receiving benefits and the numbers who are employed whilst claiming welfare payments.

Psychiatric and social history, including educational history and whether participants had ever been employed, was recorded using the Past History and Socio-demographic Description Schedule (PHSD) (World Health Organization (WHO) 1973). The PHSD was also used to code length of illness and age of illness onset defined as age at which the participant presented to psychiatric services.

The Schedule for Clinical Assessment in Neuropsychiatry (SCAN) (Wing et al 1990, WHO 1992) was used to establish a DSM-IV diagnosis of schizophrenia in the UK and Germany, whilst the French centres used the Structured Clinical Interview for DSM-IV (First et al 1997). Part of the alcohol and substance misuse data available from the SCAN allowed the coding of variables indicating lifetime history of alcohol abuse and drug abuse. All centres completed the sections of the SCAN related to alcohol and substance misuse.

Information on current symptom profile was collected through the Positive and Negative Syndrome Scale (PANSS) (Kay et al 1987; Kay et al 1989). The summary indicators from the PANSS used in this analysis were the positive, negative and general psychopathology symptom sub-scores. The general psychopathology section covers a wide variety of non-psychotic symptoms, and includes measures of anxiety and depression, uncooperativeness, cognitive symptoms, impulse control and social avoidance. Inter-rater

reliability has been reported as adequate or good (Bell et al 1992, Norman et al 1996)

Adherence to pharmacological treatment was evaluated using the Rating of Medication Influences (ROMI) scale (Weiden et al 1994). This is a reliable and valid method of assessing subjective attitudes and behaviours that influence patients' compliance with anti-psychotic medication (Weiden et al 1994). It yields a total "reasons for compliance" score, higher in people who are more willing to take medication, and a "reasons for non-compliance" score, higher in people who are more reluctant.

The European Service Mapping Schedule (ESMS) (Johnson et al 2000) was used to describe and classify the mental health vocational services available in all three sites. Its use has been described as feasible in several European countries (Johnson et al 2000). Vocational services are known to affect the employment rate in schizophrenia (Drake et al 1998), and this analysis allowed consideration of whether variation in employment rate between sites might be linked to employment service provision.

Combined training was held involving interviewers from all three sites in order to try and ensure instruments were used reliably. However, no formal assessment was made of reliability between centres. For those instruments not already available in French and German, translation followed the comprehensive procedures recommended by the WHO (Sartorius and Kuyken 1994), including back-translation.

3.3.4 Analysis

The aims of the analysis were to describe patterns of employment and to explore which candidate explanatory variables were independently associated with the odds of being employed at baseline in this large international sample. Descriptive and unadjusted analyses were carried out using the Statistical Package for the Social Sciences (SPSS) (version 11.5) and the subsequent

logistic regression using STATA (version 8). Employment was broadly defined as having any job, whether full or part-time, and whether obtained through the open labour market, sheltered vocational schemes, or the voluntary sector. A broad definition of working was used because quantitative and qualitative studies exploring the attitudes of people with schizophrenia to employment suggest that people desire a range of different types of employment, not only full-time competitive paid work (Secker et al 2001, Honey 2004, Chapter 4). Also the QOLI, from which the employment data was gathered, does not distinguish between these various types of work.

Whether a person was working according to this broad definition was the main variable used in the analyses. Within the employed group, the number in each centre who were supporting themselves solely with earnings and the numbers who were working but also claiming some form of welfare benefits were also examined.

The data was analysed in a number of stages. Descriptive analyses were conducted of patterns of employment in each centre: current rates of employment and types of jobs; the number of people employed and supporting themselves through earnings only; and the percentage of people never employed.

Using Chi-squared tests for categorical outcomes and t-tests for continuous outcomes, the associations of employment with various explanatory variables were analysed. The potential explanatory variables were derived from the literature review on correlates of employment among people with schizophrenia (Chapter 2). These were educational history, negative and positive symptom severity, gender, marital status, ethnic group, accommodation type, living conditions and general population employment rate in area of residence. Other variables available from the dataset that were of potential interest were also identified and their association with working tested. These were adherence to medication, course of illness, age at presentation to psychiatric services, length of illness, lifetime history of alcohol or drug misuse and area of residence. These additional variables were chosen

because a mechanism by which they might influence employment could be envisaged in theory and because such an effect had not been precluded by the previous literature.

German centres did not code ethnicity in the same way as the UK and French sites and German participants could therefore only be classified either as “born in Germany” or “German resident but born abroad”. Thus separate analyses were carried out for each country examining the association between ethnic group (or in the case of Germany where born) and employment.

Logistic regression was then used to identify explanatory variables independently associated with employment using the “enter method”, in which all independent variables are entered into the equation at the same time. Those variables associated with employment in the unadjusted analyses at at least the $p < 0.1$ level of significance were entered into the model as independent variables. Ethnicity was excluded as a variable in the logistic regression because of a lack of uniformity in the way it was categorised across the three countries. Lack of independence for observations regarding individuals within the same centre was allowed for in this analysis by computing robust standard errors, clustered on centre (Rogers 1993).

3.5 Results

3.5.1 Sample socio-demographic and clinical features

In total, 1208 people with schizophrenia participated in the study: 288 in France, 302 in the UK and 618 in Germany. The clinical and socio-demographic profiles of the sample are shown in table 5 and have been summarised from Bebbington et al (2005). ANOVA or Chi-square was used to test if there were significant differences between countries in any of the socio-demographic variables.

Table 5 Socio-demographic and clinical characteristics of samples

	France (N=288)	Germany (N=618)	United Kingdom (N=302)	All (N=1208)	ANOVA or Chi- square
Sex – male	200 (69.4%)	348 (56.3%)	195 (64.6%)	743 (61.5%)	P=0.0005
Age – mean (standard deviation)	39.5 (10.3)	41.5 (11.0)	40.7 (11.7)	40.8 (11.1)	P=0.05
Family situation					P=0.0001
- single	206 (71.5%)	335 (54.2%)	203 (67.2%)	744 (61.6%)	
- married	24 (8.3%)	117 (18.9%)	40 (13.2%)	181 (15.0%)	
- living as a couple	20 (6.9%)	40 (6.5%)	13 (4.3%)	73 (6.0%)	
- divorced/separated	33 (11.5%)	119 (19.3%)	43 (14.2%)	195 (16.1%)	
- widowed	4 (1.4%)	7 (1.1%)	3 (1.0%)	14 (1.2%)	
Living conditions					P=0.0001
- living alone	103 (35.8%)	205 (33.2%)	109 (36.1%)	417 (34.5%)	
- nuclear family	47 (16.3%)	170 (27.5%)	51 (16.9%)	268 (22.2%)	
- living with parents or other relatives	113 (39.3%)	108 (17.5%)	73 (24.2%)	294 (24.4%)	
- group accommodation	17 (5.9%)	84 (13.6%)	40 (13.2%)	141 (11.7%)	
- other	7 (2.4%)	51 (8.3%)	29 (9.6%)	87 (7.2%)	

	France (N=288)	Germany (N=618)	United Kingdom (N=302)	All (N=1208)	ANOVA or Chi-square
Classification of longitudinal course - episodic with residual symptoms - episodic with no residual symptoms - continuous - single episode in partial remission - single episode in full remission - other or unspecified pattern	125 (43.4%) 31 (10.8%) 108 (37.5%) 6 (2.1%) 2 (0.7%) 16 (5.6%)	315 (51.0%) 154 (24.9%) 77 (12.5%) 25 (4.0%) 14 (2.3%) 10 (1.6%)	61 (20.2%) 50 (16.6%) 119 (39.4%) 14 (4.6%) 30 (9.9%) 27 (8.9%)	450 (41.5%) 235 (19.5%) 304 (25.2%) 45 (3.7%) 46 (3.8%) 53 (4.4%)	P<0.0001
Total PANSS score-mean (standard deviation)	71.0 (21.3)	55.7 (19.8)	48.1 (15.7)	57.4 (20.9)	P<0.0001
Total CDSS Score- mean (standard deviation)	3.58 (4.1)	2.77 (3.3)	2.35 (3.4)	3.05 (3.9)	P<0.001

Gender distribution varied between countries: 64.6% of participants in the UK, 69.4% in France and 56.3% in Germany were male. The mean age was approximately 40 years in all three countries, but marital status and living conditions differed significantly. Similar numbers of participants were living alone in each country, but more German respondents were living with partners and/or children, and more French respondents with their parents. Participants in France were the most symptomatic in terms of psychosis with a mean total PANSS score of 71, followed by 56 in Germany and 48 in the UK.

3.5.2 Employment

Table 6 shows employment rates and the numbers who had never worked in each centre. The employment rate in the general population in the regions in which the centres lie is also shown. The overall employment rate of participants was 21.5%, but varied between countries and sites with rates of 12.9% in the UK, 11.5% in France and 30.3% in Germany. This compares with general population employment rates of 71.0 % in the UK, 62.2% in France and 65.4% in Germany in the year 2000 (European Commission 2002).

The proportion of people in each country who were supporting themselves entirely through working and were not receiving welfare benefits was 8.9% in the UK, 7.6% in France and 11.8% in Germany. The German centres thus had the highest proportion of people working as well as the highest proportion supporting themselves entirely through work, although the difference in the latter was less striking. The number of people in each centre who had never been employed was low, apart from in Marseille.

Table 6: Participant numbers and employment rates by site

	London	Leicestershire	Lille	Lyon	Marseille	Leipzig	Hemer	Heilbronn	X ²	P=
Regional employment rates*	64.8%	75.4%	52.5%	63.5%	56.7%	61.5%	61.2%	66.8%		
N=	150	152	101	100	87	398	120	100		
Total working (broad definition) (%)	10 (6.7)	29 (19.1)	8 (7.9)	10 (10.0)	15 (17.2)	95 (23.9)	32 (26.7)	60 (60.0)	131.2	<0.0005
Employed & supporting self with earnings only	4 (2.7)	23 (15.1)	5 (5.0)	8 (8.0)	9 (10.3)	36 (9.1)	22 (18.3)	15 (15.0)		
Working and receiving benefits	6 (4.0)	6 (3.9)	3 (3.0)	2 (2.0)	6 (6.9)	59 (14.9)	10 (8.3)	45 (45.0)		
Unemployed	140 (93.3)	123 (80.9)	93 (92)	90 (90.0)	72 (82.8)	302 (75.9)	88 (73.3)	40 (40.0)		
Total never employed (%)	22 (15.8) 139	1 (0.8) 125	9 (9.9) 91	4 (4.4) 91	28 (38.9) 72	12 (3.0) 398	8 (7.1) 112	(11.0) 100	99.3	<0.0005

*** Source EUROSTAT annual average in 2000. The figures refer to the employment rate in the regions in which the centres lie**

Table 7 describes the jobs of study participants, using the U.K Standard Occupational Classification 2000 (Office for National Statistics 2000) for the sake of uniformity. In all three countries people with schizophrenia appeared to work in nearly all sections of the job market. The commonest types of work were “elementary jobs”, such as cleaning and labouring, and “skilled trade occupations”, such as plumbing or metal work. The proportion of people working in senior official or managerial positions and as process plant and machine operatives was very small. More people in Germany were doing sheltered or voluntary work.

Table 7: Job type of those working classified by the Standard Occupation Classification 2000 UK

Occupation	UK No (%¹)	France No. (%)	Germany No. (%)
Managers and senior officials. E.g. marketing manager	1 (3%)	0 (0)	0 (0)
Professional occupations. E.g. civil engineer	4 (10%)	1 (3%)	9 (5%)
Associate professional and technical occupations. E.g. nurses, quality assurance technicians	5 (13%)	1 (3%)	7 (4%)
Administrative and secretarial occupations. E.g. credit controllers, stock control clerks	3 (8%)	2 (6%)	6 (3%)
Skilled trades occupations. E.g. motor mechanics	7 (18%)	5 (15%)	14 (8%)
Personal service occupations. E.g. travel agents	3 (8%)	2 (6%)	7 (4%)
Sales and customer service occupations. E.g. call centre agents	3 (8%)	1 (3%)	4 (2%)
Process, plant and machine operatives. E.g. textile process operative	0 (0%)	1 (3%)	2 (1%)
Elementary occupations. E.g. farm workers, labourers	11 (28%)	8 (24%)	41 (22%)
Voluntary / sheltered work	2 (5%)	6 (18%)	71 (38%)
Difficult to classify	0 (0)	4 (12%)	15 (8%)
Job data missing	0 (0)	2 (6%)	11 (6%)
Total number working	39	33	187

¹ Percentages of the total group who are working within each country are shown.

3.5.3 Employment service characteristics of the three sites

Table 8 presents the number of services and the mean number of people using these services per month. The main difference in employment service configurations, mapped using the ESMS was that the German centres had more vocational services and more placements provided within these than the other two countries. This was particularly the case for high intensity work services and high intensity work related services. These services may be sheltered workshops or social firms.

The ESMS defines high intensity work services as those offering work placements for at least 2 days a week paid at a rate at least 50% of the local minimum wage and the latter as services that offer placements 2 days a week but at a rate of pay below 50% of the local minimum wage. Out of the German centres, Heilbronn had the greatest number of patients currently in placements but mostly in supported work activities paid below 50% of the minimum wage. Few vocational services were recorded in France, but the French centres did not include social services or voluntary sector provision in their data collection. No vocational services were recorded in Leicestershire, making it unlikely that the ESMS was completed in a satisfactory way at this centre². In London there were some work activities within day centre settings but few formal sheltered or supported work schemes.

²personal communication from Leicestershire centre lead

Table 8: Number of work services available to the catchment area population and mean number of patients using these services per month

Centre	High intensity work services		High intensity work related activity services		Low intensity work service		Low intensity work related activity services	
	No of services	No of service users	No of services	No of service users	No of services	No of service users	No of services	No of service users
London	0	0	6	9.4	0	0	2	2.0
Leicestershire	0	0	0	0	0	0	0	0
Lille	0	0	2	2	0	0	3	4
Lyon	0	0	0	0	0	0	1	1
Marseille	0	0	1	1	0	0	1	17
Leipzig	2	33	4	50	4	15	2	7
Hemer	1	12	2	69	0	0	0	0
Heilbronn	0	0	2	295	0	0	0	0

3.5.4 Unadjusted analyses

Employment was significantly associated with area of residence, having a diploma or degree, living conditions, alcohol misuse, general population employment rate in area of residence, more severe positive, negative and general psychopathology symptoms, longer length of illness and illness course (tables 9 and 10). In Germany, foreign-born people were more likely to be working but no association was found between ethnic group and working in the UK or France. The associations with illness variables were particularly highly significant on these analyses, as were the associations with area of residence.

Table 9: Work and social variables

Table 3: Work and Social Variables			Association with working	
Variable	No. working/ total in group	% of group working		
			X ²	p=
Vocational Training				
No	99 /524	18.9%	3.16	0.075
Yes	147/634	23.2%		
Diploma or degree				
No	210 /1026	20.5%	6.82	0.009
Yes	43/143	30.1%		
Gender				
Male	162 /742	21.8%	0.15	0.93
Female	96/459	20.9%		
Marital Status				
Single, divorced or widowed	167 /743	22.5%	1.23	0.27
Married or cohabiting	61/254	21.1%		
Living conditions				
Alone at home	77 /417	18.5%	15.60	0.004
With partner (+/- children)	62 /268	23.1%		
With family (not partner)	69 /293	23.5%		
Supported housing	42 /141	29.8%		
Homeless and other	9 /87	10.3%		
Accommodation				
Owner occupied	40 /176	22.7%	Fisher's exact test	0.10
Rented	161/799	20.2%		
Supported accommodation	42/155	27.1%		
Hospital	12/65	18.5%		
Homeless	0/2	0%		
Other	5/10	50.0%		
Substance use				
Alcohol misuse	35/223	15.7%	5.68	0.017
No alcohol misuse	224/975	23.0%		
Drug misuse	13/90	14.4%	2.08	0.093
No drug misuse	243/1104	22.0%		
Ethnicity				
UK			Fishers exact test	0.804
White	33/234	14.1%		
Black Caribbean	4/42	9.5%		
Asian	2/13	15.4%		
Turkish / Greek	0/6	0%		
Other	0/7	0%		
France			Fishers exact test	0.347
White	30/269	11.2%		
Black Caribbean / African	1/3	33.3%		
Turkish / Greek	0/1	0%		
Other	2/14	14.3%		
Germany			6.63	0.01
Born in Germany	168/577	29.1%		
German but born abroad	17/34	50%		
Local employment rate				
51-55%	8/101	(7.9%)	Test for linear trend	<0.0005
56-60%	15/87	(17.2%)		
61-65%	147/767	(19.2%)		
66-70%	60/100	(60%)		
71-75%	29/152	(19.1%)		
Years of education				
	Mean for workers (SD)	Mean for non-workers (SD)	t =	p =
	10.2 (2.0)	10.1 (2.1)	-0.62	0.54

Table 10: Work and clinical variables

Variable	Mean score for workers (SD)	Mean score for those not working (SD)	Difference between workers and non-workers	
			t	p=
	N=259 ³	N=948		
PANSS positive symptoms	11.2 (4.9)	12.7 (5.7)	4.22	<0.0005
PANSS negative symptoms	14.1 (6.9)	16.2 (7.8)	4.34	<0.0005
PANSS general psychopathology	26.5 (9.4)	30.0 (10.8)	5.13	<0.0005
Length of illness	14.3 (9.1)	16.0 (10.0)	2.61	0.009
Age at presentation to psychiatric services	25.5 (7.7)	26.5 (8.5)	1.70	0.090
Reasons for compliance	2.14 (0.44)	2.09 (0.45)	1.37	0.17
Reasons for non-compliance	1.68 (0.61)	1.60 (0.56)	-1.78	0.075
	No. working/ total no. in category	% working in category	χ^2	p=
Overall illness course				
Episodic with inter-episode symptoms	123/509	24.2%	52.07	<0.0005
Episodic without inter-episode symptoms	75/234	32.1%		
Continuous	25/304	8.2%		
Single episode in partial remission	10/45	22.2%		
Single episode in full remission	14/46	30.4%		
Other/unspecified course	9/54	16.7%		
Illness course characterised by prominent negative symptoms				
Yes	76/395	19.2%	1.67	0.20
No	182/809	22.5%		

³ There are missing values for some variables: the greatest number of missing values is for reasons for compliance, where there are 935 ratings for the non-workers and 256 for the workers.

3.5.5 Logistic Regression

Table 11 shows the final regression model, which explained 19% of the variance in employment status. Vocational training, regional employment rate, negative symptom score, alcohol misuse, duration of illness and reasons for non-compliance score were all entered into the regression, but did not reach the $p=0.05$ threshold for significance and were omitted from the final model. People with schizophrenia living in Leicestershire, Marseille, Leipzig, Hemer and Heilbronn all had higher odds of being employed than those living in London. Living with family (other than a partner), having a degree or a diploma, and having experienced only one episode of illness with full remission also improved the odds of working. A continuous illness course, higher general psychopathology scores on the PANSS, earlier onset of illness, and a history of drug misuse all reduced the odds of current employment. A higher PANSS positive symptom score was associated with a greater likelihood of working, a reversal of the effect observed on unadjusted analysis, but this effect was a weak one.

Table 11: Variables significantly associated with working (broad definition) in logistic regression

Number of subjects included in the analysis	1158	
Percentage correctly classified by model	80.14%	
Pseudo R Squared⁴	0.19	
Variable	Odds ratio (95% confidence interval)	p =
<i>Living in⁵:</i>		
Leicestershire	3.68 (2.84 to 4.77)	<0.0005
Marseille	6.63 (2.02 to 21.78)	0.002
Leipzig	3.70 (1.96 to 7.00)	<0.0005
Hemer	9.54 (4.05 to 22.44)	<0.0005
Heilbronn	36.37 (17.45 to 75.78)	<0.0005
Living with family (not partner) ⁶	1.41 (1.12 to 1.78)	0.003
Diploma or degree	1.75 (1.07 to 2.88)	0.026
Drug abuse	0.27 (0.13 to 0.58)	0.001
<i>Illness course⁷</i>		
Continuous illness course	0.44 (0.29 to 0.68)	<0.0005
Single episode of illness in full remission	1.40 (1.24 to 1.57)	<0.0005
Age of first presentation to psychiatric services.	0.98 per year (0.96 to 1.00)	0.033
General psychopathology symptoms (total score)	0.95 per point on PANSS sub-scale (0.93 to 0.98)	<0.0005
Positive psychotic symptoms (total score)	1.03 per point on PANSS sub-scale (1.00 to 1.06)	0.038

⁴This provides an estimate of the variance explained by the model.

⁵The comparison centre is London. Lille and Lyon were not significantly different from London.

⁶The comparison category is living alone

⁷The comparison category is single episode, partial remission

3.6 Discussion

3.6.1 Comparisons of employment rates between centres

This is the first international comparative study to substantially explore employment patterns and the variables associated with working in a representative community sample of people with schizophrenia. As in other recent studies (Perkins and Rinaldi 2002, UK700 Group 1999) the employment rate in the UK sample was low, especially in London.

The rate in France is equally concerning, at approximately a third of the German rate. The large numbers of unemployed people with schizophrenia represent a significant financial cost (Huxley and Thornicroft 2003) to the welfare states of these three countries, and indicate considerable social exclusion among the mentally ill.

There was still greater variation in employment rates if centres rather than countries were analysed. Thus there was an approximately ten-fold difference in employment rate between London and Heilbronn. This is likely to be in part related to the characteristics of the areas from which the samples were drawn. The London sample was recruited from Islington, an inner city area of considerable social deprivation. The employment rate was similarly low in the urban centres of Lille and Lyon. People recruited from the more affluent and suburban area of Leicestershire had a higher employment rate. City living also appears to have an adverse effect on employment in people with severe mental illness in the USA (Drake et al 1998). The large variations between centres, which were not accounted for by differences in clinical and socio-demographic characteristics of the samples, suggest that social and service factors that vary between countries and regions are likely to be important.

3.6.2 Comparing employment rates in people with schizophrenia with the general population

Compared to the rates in the general population, the employment rate among people with schizophrenia in all three countries was low. Uni-variate investigation of the relationship between regional general population employment and employment rates among the mentally ill appeared to lend some support to previous research (Warner 2004, Cook et al 2006) suggesting higher general population employment rates are associated with better employment prospects for people with schizophrenia. However, multivariate analysis did not substantiate this association. No such relationship was found in the CATIE study in the USA (Rosenheck et al 2006) or from analysis of the 3 year US-SCAP follow-up data (Salkever et al 2007).

A potential reason for the discrepancy between the finding in this analysis that local employment rate does not have an affect on the rate in people with schizophrenia and the results of Cook et al (2006) is the type of statistical methods used. Cook and colleagues used hierarchical multilevel modelling and found general population employment to influence the rate of working in people with mental illness, although the sample was very diagnostically mixed. Multi-level modelling is a more satisfactory method of simultaneously investigating the effects of individual factors and area level effects on outcome but does require about 20 plus centres to be a powerful technique, something that was not available in the EuroSC study.

The nature of the relationship between the employment rate among the people with schizophrenia and local social factors, including local employment rate and the ethnic and age structure of the population is likely to be complex, not least because of the intervention of mental health services. Also using local employment rate as a proxy of local labour market conditions is unlikely to fully encompass differences in the types of job available at the different centres. The types of work available are important because the level of access to relatively unskilled and undemanding jobs may especially affect people with schizophrenia (Nickell 2004).

Other local and national factors which may contribute to variations between centres include professionals' and patients' attitudes and values regarding the feasibility and importance of work, the attitudes of employers and the public, the stigma patients experience in the labour market and differences in benefits systems and employment law. The first two are explored further in UK samples, later in this thesis.

In most areas, the great majority of study participants had worked at some stage, the exception being Marseille, where a substantial proportion of the sample (38.9%) had never worked and the local general population employment rate was also low. The fact that most participants had worked earlier in their lives but no longer did so indicated that few people had recovered fully in their social functioning. That services may not currently be achieving the best possible social recovery is suggested by the finding that even among those who had fully recovered after a single episode, the employment rate remained just below 30%.

3.6.3 Vocational services, benefits payments and employment rates

The variations in employment rates between areas were even larger than those between countries, and persisted when adjustment was made for patient characteristics and regional general population employment through regression analysis. Various societal factors that might account for these variations have already been discussed. Another possible explanation is differences in the provision of vocational services and placements.

It is not possible to be confident about the quality of the ESMS data obtained in Leicestershire and there were deficiencies in data collection in France also. Whilst these caveats are explored further in the limitations section, the available data indicates that German centres had both the greatest numbers working in sheltered settings or social firms and also relatively large numbers supporting themselves entirely through their earnings without recourse to state

benefits. This suggests that good availability of opportunities for combining work and benefits does not necessarily lead to people getting stuck in this situation, and may be associated with a greater proportion of people supporting themselves fully through open market earnings, though a causal relationship is not proven.

The situation found in the German centres, where a greater proportion of people were working whilst still claiming benefit, is reminiscent of the recent strategy of the US Government, which aims to improve the employment rate of the disabled. Although primarily directed at increasing open market work, the Ticket to Work and Work Incentives Act in the USA increases the earnings disregard so that people may have a greater income from work before benefits are cut.

3.6.4 Occupation

In a large household survey in the USA (Mechanic et al 2002) people with serious mental illness had broadly the same occupational profiles as people in the general population. This was not the case in the EuroSC study sample. Although there was no direct comparison group from the general population in this study the jobs of people with schizophrenia appeared much more weighted to low paid elementary and semi-skilled roles in comparison to the proportions found in the general population (Begum 2004, European Commission 2002).

In studies of vocational interventions, those successful in obtaining work most often work in low paid, transitory jobs (Lehman et al 2002). These entry-level jobs also tend to offer the least amount of job security and this risk may act as a barrier to working if the process of reclaiming benefits if the job is lost is seen as cumbersome and slow. In other words people may feel that the inherent risks of working in such jobs is not worth the risk of relinquishing their benefits.

There were no large differences between the proportions of people in each country that worked in various types of job, but the numbers were small. Previous studies have suggested that people with schizophrenia tend to be in positions involving low levels of interpersonal interaction (Bacani-Oropilla et al 1991; Morgan and Gopaldaswamy 1983). "Elementary" occupations such as cleaning and labouring may be of this nature, as well as some skilled trades. In these types of positions it is possible that deficits in social skills, or the cognitive problems associated with schizophrenia are less debilitating and therefore the chance of good occupational functioning higher. However it is impossible to say from this data whether people with schizophrenia actually choose these positions in preference to others or whether they are forced into them if they wish to work because of stigma or the deficits associated with the illness.

Very few people with schizophrenia were in managerial and senior official positions where training periods may be long, a series of promotions required and an episodic illness thus particularly damaging. It is surprising that more people were not working in information technology, given the expansion of this industry over the last decade. Overall, it appears that a diagnosis of schizophrenia is probably not a bar to doing any kind of job, but makes entry into certain job types less likely.

3.6.5 Social correlates of employment in people with schizophrenia

Living with family (other than a partner) was associated with a greater likelihood of working, persisting after adjusting for other independent variables. This replicates previous study findings (Rogers et al 1991, 1997, O'Brien et al 2003) and may reflect better social support enabling better social recovery.

Ethnic group was not significantly associated with employment in the UK and French samples although place of birth did emerge as important in Germany in the unadjusted analyses. Small numbers of ethnic minority group members

limit conclusions about this. The effect of cultural background and values on whether people with schizophrenia work is an under-researched area, but this may have a role in explaining variations in employment rates.

In the EuroSC sample, number of years of general education was not significantly associated with work in the regression analysis. However having a diploma or degree was important in explaining work status and in part this finding is a replication of a number of other, mainly American studies (Salkever et al 2007, Burke-Miller et al 2006) that find that the acquisition of more than a high school education is linked to future employment. Obtaining a tertiary education may also reflect generally better pre-morbid functioning, associated with better overall outcomes, and possession of some qualifications may also broaden choice for those seeking to re-enter the labour market.

3.6.6 Clinical correlates of employment

Co-morbid drug misuse was associated with lower odds of working in the EuroSC study and this diverged from the findings of previous cross-sectional and prospective studies (Goldberg et al 2001, Bond et al 2001a). However the current analysis does support a previous study indicating high levels of social exclusion among people with 'dual diagnosis' (Todd et al 2004). Substance misuse may well make job seeking and good occupational functioning more difficult.

There have been contradictory findings in previous studies about the effects of positive and negative symptoms of schizophrenia on employment status (Anthony and Jansen 1984, Cook and Razzano 2000, Chapter 2). Positive and negative symptoms were significantly associated with employment in the unadjusted analyses but no clear relationship was found in the regression model. There was no significant association with negative symptoms, but a marginally significant ($p=0.038$, $OR=1.03$ (CI: 1 to 1.06)) tendency for more

positive symptoms to be associated with a greater likelihood of working. Given the confidence intervals this is unlikely to be a real effect.

The absence of the anticipated relationship between greater positive and negative psychotic symptom severity and lower likelihood of working may well be due to the association between higher psychotic symptom scores and a continuous illness course, which substantially reduced the odds of employment in this analysis. However it would appear at least from this cross sectional analysis that the presence of positive or negative symptoms per se should not be thought of as necessarily preventing people with schizophrenia entering the labour market.

The symptoms assessed by the general psychopathology section of the PANSS were related to employment status, although the effect was not large. This finding may be explained by the possibility that psychiatrists may not routinely treat symptoms like anxiety, depression, social avoidance, poor impulse control and cognitive deficits very vigorously, or treatment response may be poor.

People who had suffered a single episode of illness with full recovery had greater odds of working though the absolute employment rate was low, whilst those who had a continuous illness course were less likely to be in employment. This is comparable to the results of a retrospective case note study of 436 people with 1st episode psychosis followed up over 6 years (Rosen & Garety 2005). This pattern suggests that it is the cumulative losses over time associated with a lack of recovery that particularly damage employment prospects and also that being ill all the time simply stops a person working.

3.6.7 Limitations specific to the EuroSC study methodology

Because the study did not formally check the reliability of ratings, country level comparisons of data from interviewer-rated instruments such as the PANSS

warrant cautious interpretation. However employment status was self-reported with only a binary response possible and is thus less likely to be subject to problems of reliability.

Although efforts were made to ensure consistent and comparable procedures in all centres, the service structures were different, and recruitment bias cannot be excluded. It is unlikely however to explain a large amount of the variation in employment rates, given that the U.K sample which had the least severe symptoms had a very similar low rate of employment to the French sample who scored highly on symptom severity.

There were differences between centres in the way data were collected using the ESMS. Whilst the French centres did not include services provided by the social or voluntary sector, all other sites did. Also as mentioned above there is a low level of confidence that the ESMS was completed in a satisfactory way in Leicestershire given that this centre did not code any vocational services at all. It is not possible to say how more robust data from these sites would have affected the analysis.

The problems with ESMS data collection in Leicestershire raise the spectre of poor quality data from the other sites. A number of associated findings about services in general described by other investigators lend support to the differences in vocational services described between Germany and London by the ESMS. The London UK centre is reported to have less in the way of services providing day-time and structured activities than Leipzig (42.6 v 71.7 users per 10000 inhabitants per working day) (Becker et al 2002, Angermeyer et al 2004). Moreover, the number of unmet needs of people with schizophrenia was 2.3 in London compared to 1.0 in Leipzig (Kilian et al 2001) suggesting more comprehensive service provision at the German centre. Therefore there may be variations in service provision in London and Germany, and it is possible that the differences in vocational services reported in the current analysis form part of this pattern.

The candidate variables used to predict the odds of working were limited to those that had already been collected as part of the EuroSC study. Thus data on work history, a consistent and powerful predictor of future employment were not available and could not be controlled for in the regression analysis. Also information on people who did not consent was not collected and thus it is not possible to provide information on non-responders or to examine if this caused a bias.

3.6.8 Limitations specific to this analysis

The definition of employment used was a broad one and it was not possible to identify accurately the group who were in open market employment strictly defined, because of the extent to which the QOLI collects this information. However it is likely that those who were working without recourse to state benefits form a major part of this group.

Ideally a hierarchical form of analysis, such as multilevel modelling should be used to explore the effects of country and local level variables on employment status at individual level. However, whilst this analysis had excellent power for the investigation of individual level explanatory variables, the three countries and eight centres were insufficient for such a multilevel analysis. The data therefore did not allow a substantial exploration of the effects of national and regional level variables on employment among the mentally ill. In addition, attribution of regional employment rates to individuals is a somewhat unsatisfactory method of exploring the relationship between local and individual characteristics. As discussed previously, regional employment rate is likely to be a less than perfect proxy of local labour market conditions. Despite these shortcomings the methodology used in this analysis is very similar to other studies investigating the influence of local employment levels on people with schizophrenia and has produced comparable results.

Regression modelling using sets of variables that have substantial inter-correlations, as in this analysis, results in models that are relatively susceptible to change with small alterations in the variables included. This

should be borne in mind especially in relation to those variables that are marginally significant in the final model. A further caveat is that no adjustment such as the Bonferroni correction was made for multiple testing. Thus findings that are close to the $p=0.05$ level of significance should be treated with caution, although most of the significant associations found in the final regression were in fact at at least the $p<0.001$ level.

In any cross sectional analysis like this, interpretation must be tentative, given that causation cannot be assigned.

3.7 Summary

In summary, the analyses in this chapter suggest that the rates of employment in three European countries are low though there are country level and regional variations in the rate. The rates appeared to be influenced by the level of vocational services available to people. People with schizophrenia are able to work in all sections of the job market although most work in elementary occupations or semi-skilled trades. In this cross sectional dataset both clinical and social factors appear to be important in explaining whether a person has a job.

Chapter 4

The predictors of a change in employment status in people with schizophrenia: Analyses of the 2-year follow up data from the EuroSC study.

4.1 Introduction

The analyses in Chapter 3 explored the correlates of having a job for people with schizophrenia using cross-sectional data. Using prospective data to investigate the predictors of getting a job would enable a fuller understanding of the correlates of employment in people with schizophrenia. By their nature evaluations of the effectiveness of vocational interventions examine factors associated with getting a job over time. The correlates identified by such studies are often inconsistent (Rogers et al 1991, Fabian 1992, Burke Miller et al 2006, Catty et al 2008).

In the current literature there is only very limited information available on the factors associated with losing a job in people with schizophrenia. All previous studies are of recipients of vocational services of one form or another. They are frequently based on small samples and are often concerned with the nature of job terminations as opposed to the factors associated with job loss. For example at an individual level, interpersonal difficulties and an inability to cope with the demands of a job have been reported to be important in explaining why people with SMI lose employment (Wong et al 2001, Becker et al 1998). Investigations of clinical and socio-demographic factors related to job loss are rare.

Improving our understanding of the factors that influence getting and losing a job could help target interventions to improve occupational outcome. Thus this chapter addresses part of Aim 3 of this thesis; that is, to examine the associations of obtaining and losing work in a representative and

prospectively studied sample of people with schizophrenia living in the community.

4.2 Aim

- To describe and analyse the predictors of obtaining and losing employment in people with schizophrenia.

4.3 Methods

4.3.1 Sample and procedures

This analysis is based on the 2-year follow-up data from the EuroSC study. The sampling methods, study sites and instruments used have already been described in Chapter 3 and therefore, to avoid repetition, will not be described again in detail here. In summary the naturalistic study was based in the UK, France and Germany and collected data from a representative sample of people with schizophrenia living in the community who were in receipt of secondary mental health services.

Participants were interviewed at baseline and at 6 monthly intervals and a battery of instruments administered. Initial and final assessments took around three hours, the intervening assessments somewhat less. Assessments took place in a venue convenient to the patient, whether at home or in a clinical facility.

4.3.2 Coding of employment status change

As described in Chapter 3 employment data from the QOLI was used and further information on this instrument is available in Appendix B. A number of different ways of categorising employment status change over time were initially formulated to decide which method captured the greatest number of transitions between employment statuses. Firstly the level of flux in employment rate every six months was examined and this is shown in table

12. Although there was a significant change in employment rate over the first 6 months this appeared to be due to sample attrition. The proportion of people employed after 6 months changed very little.

An alternative method of coding employment status change was used to maximise the numbers available for analysis and ensure adequate statistical power. Thus using the six monthly follow-up data with regards to work status, four new employment variables were coded. These were employment throughout the follow-up period, employment at baseline with a subsequent loss of a job over 2 years, unemployment throughout, and unemployment at baseline but subsequent employment during the 2 year follow-up.

Using this method of coding, larger numbers were categorised as having a change in employment status because the follow-up period effectively increased from 6 months to 2 years. However as a result only the first transition in employment status over the 2 years was coded whether any further changes in occupational status occurred or not. Therefore some sensitivity was lost as those experiencing multiple employment transitions during the follow-up were not differentiated from those undergoing a single change.

Table 12: Six monthly employment rates in the total sample

Assessment point	Numbers employed / unemployed	Employment rate (%)
Baseline	259/948	21.5
6 months	268/749	35.8
12 months	244/706	34.6
18 months	215/636	33.8
24 months	206/599	34.4

4.3.3 Analysis

The statistical program STATA (version 8) was used to complete the analysis. Initially the proportions changing employment status was described by centre and Chi-square used to test whether this differed significantly between the centres.

In order to identify which potential explanatory variables independently predicted employment status change, two separate logistic regressions were completed using the enter method. The sample for the first was all study participants who were employed at baseline and for which there was adequate follow up data (N=259) and the dependent variable was whether or not they had experienced a loss of employment over the following two years. The sample for the second was all those who were unemployed at baseline (N=948) and the dependent variable was whether or not they had obtained employment over the subsequent two years. As a short hand these outcome variables are referred to as “losing a job” and “getting a job” hereafter.

Variables that were associated with employment at the $p < 0.1$ significance level in the unadjusted analysis of the cross sectional data (Chapter 3) were used as potential explanatory variables in the current analyses. These variables were vocational training, having a diploma or degree, positive and negative psychotic symptom severity, general psychopathology symptom severity, living conditions, area of residence (study centre), general population employment rate in area of residence, the reasons for non compliance score, course of illness, age of illness onset, length of illness and lifetime history of alcohol or history drug misuse. The same potential explanatory variables were used for the getting a job and losing a job analysis. Again a lack of independence between observations of individuals within the same centre was allowed for in the analysis by computing robust standard errors, clustered on centre.

4.4 Results

4.4.1 Employment status change

Table 13 shows the employment status change by centre over the 2 year period of follow-up. Approximately 13% of people in the original sample stayed employed throughout the 2 years with 8.5% losing their job and 14.4% getting a job. The majority (64.3%) of participants however, remained unemployed throughout.

There was a wide range in the proportion of people who either lost a job or obtained employment by centre. London had the lowest proportion of people losing a job, yet amongst the highest rates of people getting a job. The German centres appeared to have the highest fluctuations in employment status with the frequency of change being particularly high in Heilbronn, which also had the highest employment rates at baseline.

Table 13: Change of employment status by centre

Centre	Unemployed throughout		Lost a job		Employed throughout		Got a job		Total	
	No	% within centre	No	% within centre	No	% within centre	No	% within centre	No	%
London	104	75.4	4	2.9	5	3.6	25	18.1	138	12.7
Leicestershire	103	68.2	12	7.9	15	9.9	21	13.9	151	13.9
Lille	66	80.5	3	3.7	4	4.9	9	11	82	7.6
Lyon	81	89	5	5.5	2	2.2	3	3.3	91	8.4
Marseille	48	68.6	5	7.1	7	10	10	14.3	70	6.4
Leipzig	215	62.1	42	12.1	40	11.6	49	14.2	346	31.9
Hemer	63	54.8	9	7.8	22	19.1	21	18.3	115	10.6
Heilbronn	18	19.4	12	12.9	45	48.4	18	19.4	93	8.6
Total	698	64.3	92	8.5	140	12.9	156	14.4	1086	100
P value	<0.0001		0.014		<0.0001		0.039			

4.4.2 Predictors of getting a job

A range of area level and individual level variables independently predicted getting a job over the 2 year follow-up period and these are summarised in table 14. The regression model explained approximately 15% of the variance in the “getting a job” variable. Thus, being resident in Marseille, Leipzig, Hemer and Heilbronn and higher regional general population employment rate increased the odds of people with schizophrenia getting a job. Living in Lyon, older age of illness onset, longer length of illness, having a continuous illness course and more severe negative psychotic symptoms all reduced the odds of getting a job.

Having experienced a single episode of illness, which was now in full remission surprisingly, also reduced the odds of getting a job. Initially I assumed that this unexpected finding was due to low numbers of people in each of the illness course categories. Therefore, the illness course variable was recoded in a number of ways to increase the numbers in each category. These modifications of the illness course data included: pooling those who had experienced a single episode with full or partial remission into a single group and using people who had experienced an episodic course without inter-episode symptoms as the reference category; creating 3 pooled categories coded as episodic with inter-episode symptoms together with continuous, episodic without inter-episode symptoms, and single episodes; and finally entering the illness course categories as separate binary variables into the regression instead of a single variable with a number of categories. However with all these various ways of categorising illness course, a single episode of illness remained associated with significantly lower odds of getting a job. The effect was also not attenuated by removing length of illness (which is likely to be associated with having a single episode of illness) from the list of potential explanatory variables.

Table 14 ***Predictors of getting a job**

Number of subjects included in the analysis	773	
Pseudo R Squared	0.15	
Variable	Odds ratio (95% confidence interval)	p =
¹ <i>Living in:</i> Lyon Marseille Leipzig Hemer Heilbronn	0.19 (0.13 to 0.28) 3.25 (1.24 to 8.55) 1.76 (1.13 to 2.73) 4.94 (2 to 12.22) 7.1 (3.54 to 14.22)	<0.0005 0.017 0.012 0.001 <0.0005
Regional general population employment rate	1.03 (1.001 to 1.065)	0.041
Length of illness	0.92 per year (0.88 to 0.97)	0.001
Age of illness onset	0.97 per year (0.94 to 0.99)	0.013
² <i>Illness course</i> Continuous illness course	0.47 (0.23 to 0.97)	0.041
Single episode of illness in full remission	0.6 (0.39 to 0.93)	0.024
Negative psychotic symptoms (total score)	0.92 per point on PANSS sub-scale (0.87 to 0.98)	0.01

¹ comparison category is living in London

² comparison category is single episode in partial remission

* at the 5% significance level

4.4.3 Predictors of losing a job

The factors associated with losing a job are shown in table 15. Fewer variables were independently associated with losing a job, probably because of the smaller number of participants providing data for the analysis. The model explained 13% of the variance in the dependent variable, “losing a job”. Previous vocational training reduced the odds of losing employment, whilst living in Lyon or Leipzig, harmful use of alcohol and more positive psychotic symptoms at baseline all increased the odds.

Table 15 ***Predictors of losing a job**

Number of subjects included in the analysis	213	
Pseudo R Squared	0.13	
Variable	Odds ratio (95% confidence interval)	p =
¹ <i>Living in:</i> Lyon	13.3 (5.31 to 33.29)	<0.0005
Leipzig	2.3 (1.39 to 3.81)	0.001
Harmful use of alcohol	1.17 (1.01 to 1.35)	0.035
Vocational training	0.49 (0.28 to 0.88)	0.016
Positive psychotic symptoms (total score)	1.12 per point on PANSS sub-scale (1.07 to 1.17)	<0.0005

¹ comparison category is living in London

* at the 5% significance level

4.5 Discussion

4.5.1 Area level associations of employment status change.

Centre was important in explaining employment status change although the p values were not as significant as in the cross sectional analyses, possibly because of the smaller sample size used in this analysis.

Although the absolute numbers are small the London centre had the lowest proportion of people who lost a job over 2 years as well as having a high percentage of people getting a job in comparison to the other centres. This would suggest that people with schizophrenia who had work at baseline were relatively stably employed, and that there was greater scope for getting a job in London in comparison to other centres. There are a number of potential explanations for this.

There has been a steady improvement in the economic climate in the UK and especially in London over the last 10 years (Office for National Statistics 2006). Between 2000-2005 the UK had one of the strongest economies in Europe with a quarterly GDP, which was higher than the average for the European Union and for members of the “Euro zone” (EuroStat 2006). This generally better economic landscape may mean that people in London had a better opportunity to obtain and maintain employment because of greater demands for labour. Additionally in London the rate of employment in people with schizophrenia was so low at baseline that there may have been a potentially greater pool of people who were well enough to work but not doing so in comparison to the other centres.

Another possible reason for the pattern of job gain and loss described in London may be Government policy. The National Service Framework for Mental Health (Department of Health 1999) imposed a duty on mental health trusts to tackle the social exclusion of the mentally ill and this as well as a number of other policy initiatives may have produced material investment in getting people with schizophrenia into employment.

Overall the French centres tended to have a low proportion of people who lost or obtained work over the two years. Given the low levels of employment at baseline in people with schizophrenia as well as the general population, this stasis suggests an especially poor outcome in these centres. Again looking at labour conditions offers potential explanations for the pattern of low employment status change found in France. For example, the extent to which workers are offered legal protection in France is different to many other countries. France is frequently said to have a “rigid economy” (OECD 2004). By international standards workers in France are afforded a high level of employment protection through a range of legislative measures as well as employer attitudes (Butchemann & Walwei 1996). Thus it is possible that having obtained work, people with schizophrenia in France are protected from losing it to some extent by these legal frameworks and social attitudes. The very same frameworks however may act as barriers preventing people who may already be discriminated against by employers from initially obtaining a job.

People living in Lyon appeared to fare particularly badly as this centre was an independent variable in both regression models, reducing the odds of getting a job and increasing the odds of losing work. In Marseille about 14% of people were able to obtain work. The Marseille centre had a comparatively high rate of employment in people with schizophrenia at baseline partly boosted by people working whilst claiming benefits. Living in Marseille increased the odds of getting a job also.

A different pattern of employment status change is apparent in the German centres. The rates of people losing a job and getting a job are in the upper end of the range suggesting a higher state of flux in employment status in people with schizophrenia living in Germany. Indeed living in the Leipzig centre was an independent predictor of both losing and getting a job in the regression analyses and being resident in Hemer and Heilbronn increased the odds of obtaining a job also.

People in Germany had the highest rates of work using a broad definition as well as work where they were supporting themselves entirely through a salary or wages. Additionally the level of specialist employment services available as well as of sheltered or voluntary work was high. It is likely that the degree of flux in employment status in Germany is at least partly attributable to this additional tier of specialist employment services which acts to buffer people between unemployment and full open market work. It is likely also that it is relatively straightforward to move into and out of sheltered work and far less financially risky than the switch into open work. The relative ease with which people can move in between these tiers may encourage people to try sheltered or voluntary work. Thus, it is possible that the provision of such services may encourage more people into all types of employment whether this is fully sheltered work, in social firms or within the open market.

In this analysis of the cohort data, higher regional employment rates increased the odds of getting work, consistent with some previous literature (Warner 2004, Cook et al 2006). Although significant, the effect was not large, possibly because centre is associated with regional employment rate. Although labour market conditions may have some effect, the fact that general population employment only weakly explained getting a job suggests that there is scope for improving the occupational outcome of people with schizophrenia with tailored specialist employment services whatever the employment rate in the general population.

4.5.2 Predictors of getting and losing a job

Apart from area of residence, different factors explained getting a job and losing a job, suggesting that the predictors of employment status change are specific to the transition in question.

4.5.2.1 Getting a Job

The predictors of getting a job were similar to previous cross-sectional and prospective studies of the factors associated with being in employment.

People who had a longer length of illness had lower odds of getting a job over the follow up period, consistent with the theory that the socially damaging effects of established schizophrenia tend to persist (Reid et al 2001) after an initial “critical period” (Birchwood et al 2000). A longer length of illness with more illness episodes is likely to be severely disruptive to the stability of work functioning as well as progressively reducing morale and motivation to work, a psychological effect found in the long term unemployed in the general population also (Bartley 1994).

An older age at presentation to psychiatric services reduced the odds of getting a job both in the cross sectional (Chapter 3) and this analysis. This effect may partly be explained by the association of older age at presentation and longer duration of untreated psychosis (DUP) (Amminger et al 2002, Barnes et al 2000) as a lengthier DUP has also been correlated with poorer occupational functioning in the longer term (Harris et al 2005).

Continuous illness course also reduced the odds of getting a job, a result identical to the cross-sectional analysis of the associations of working. This type of illness course is suggestive of a more severe form of schizophrenia with a generally poorer outcome in all domains. It was surprising that experiencing a single episode of illness and being in full remission at baseline also reduced the odds of getting a job over the following 2 years. It may be that people who have suffered only a single episode of illness and recover fully are less likely than others to receive rehabilitative input. Additionally this result may be due to restricting the sample in this analysis to those people who were unemployed at baseline. Thus people with a single episode who were able to work at baseline were excluded, leaving those with a single episode who were less able to work for reasons unrelated to illness course. Overall the finding in this analysis that a single episode of illness reduces the odds of obtaining a job in the future, is one in which there should be a low level of confidence given that it directly contradicts the analysis of the cross sectional data.

Unlike the baseline analysis, general psychopathology symptom scores did not prove to be significant in predicting getting a job. Instead negative symptoms were significant and reduced the odds of obtaining work prospectively, similar to a number of other studies (McGurk & Mueser 2004). Deficits in self care, motivation and volition may make it unlikely that a person will be able to actively search work out, apply for jobs and then adequately present themselves at interview.

4.5.2.2 Losing a job

In the EuroSC study cohort, loss of employment was predicted by having more severe positive symptoms at baseline. A plausible explanation is that although symptoms such as delusions, ideas of reference or hallucinations do not necessarily prevent a person obtaining work, coping with them on a day to day basis over a period of time may affect work performance or result in interpersonal problems with work colleagues. These difficulties in themselves may lead to job loss if employment is short term and transitory with little legal protection.

Although in this analysis baseline positive symptoms increased the odds of job loss over the next 2 years, previous research suggests that a closer temporal relationship between symptom severity and job loss may also exist. An exacerbation of psychotic symptoms was identified as one of the important causes of the 23 early terminations from vocational rehabilitation in a prospective study of 123 participants (Watzke et al 2006).

Alcohol misuse at baseline also increased the odds that a participant lost their job over the 2 year follow-up period in the current analysis. Although it is not possible to be certain of the causal direction this suggests that the misuse had an adverse affect on occupational functioning similar to the association found in general population surveys (Pirkola et al 2000).

Previous vocational training appeared to provide some protection against losing a job for people with schizophrenia. This may partly be because the

needs of employers may not be so easily met from the pool of unemployed people as may be the case for occupations, which require a low skill level. Education and training was important in explaining job loss in another follow-up study based in the USA, which used a regression model to investigate employment retention. Over a 6-month period, low previous educational attainment predicted job loss in a sample of 159 people with schizophrenia in open market work (Salkever et al 2003).

Regional employment rate did not have an effect on whether people lost a job. It may be that whilst area level variables are important in determining whether someone is able to obtain employment, once in it, these factors become less important in whether people are able to maintain it.

4.5.3 Limitations

The limitations of the study design and methodology of the EuroSC study have been discussed in Chapter 3. Although the study collected data at 5 time points, a more sophisticated statistical analysis was not possible because the frequency of employment status change was very low over individual six monthly periods. An analysis of the change in employment status over multiple time points would have resulted in samples with very low numbers and consequently poor power to detect significant predictors of change.

The regression models explained a relatively small amount of variance in change in employment status, even though a substantial number of potential explanatory variables were used. This may be because of the essentially social experience of getting or losing a job, with multiple individual and area level factors that were not included in the analysis having an influence. Examples of these potentially important factors include the personal wishes of participants to leave or get a particular job, interpersonal problems with work colleagues, the workplace climate, cognitive problems, stigma and the availability of other suitable work in the labour market.

The dependent variables were getting a job and losing a job at any point over the 2 year follow-up. Categorising employment change in this way means that it is likely that these variables included people who had more than one transition in their work status during the 2 year time frame. However the current analysis was only sensitive to the first change of employment status. The inclusion of the subset of people who experienced multiple transitions in status was designed to maximise the power of the analysis. It may however have weakened the associations of some of the potential explanatory variables to the dependent variables because those who change work status frequently may represent a significantly different group to those who only changed their status once over the two years.

4.6 Summary

Area of residence and local labour market conditions appear to be important in explaining whether people with schizophrenia obtain work in this prospective analysis. Age of illness onset, illness course and negative symptoms were also important. Harmful use of alcohol and more positive symptoms at baseline increased the odds of losing a job over two years whilst having previous vocational training was protective.

Chapter 5

The effects of employment status on other outcomes: An analysis of the follow up data from the EuroSC study

5.1 Introduction

Thus far this thesis has examined the explanatory variables that are associated with employment status where this has been the main outcome of interest. However, whether employment status is correlated with other outcomes is an issue of importance to service users, clinicians and policy makers alike. Also the arguments for investing in services that help people gain work could be substantially aided if work was also found to have a positive influence on other aspects of psychological health and well being in people with schizophrenia. The evidence that this is the case is not robust but the current literature discussed in chapter 2 suggests that being in work may be associated with better global functioning, a reduction in positive psychotic symptoms and better quality of life.

This chapter addresses aim 4 of this thesis; that is to investigate whether employment status is correlated with other outcomes.

5.2 Aim

- To examine whether employment status over a 2 year period is associated with a change in psychotic symptoms, depression, general level of functioning and general life satisfaction at 2 years.

5.3 Methods

5.3.1 Sample and choice of outcome measures

This analysis is based on the baseline and 2 year follow-up data from the EuroSC study. The sampling methods, study sites and instruments used have already been described in Chapter 3 and therefore will not be repeated here.

The outcomes chosen for study were severity of positive and negative psychotic symptoms and general psychopathology symptoms, general level of functioning, and general life satisfaction, a subjective component of quality of life. Previous research, as discussed in Chapter 2, indicates that these may be associated with employment status. Additionally depression was selected as an outcome measure for study because unemployment is known to be associated with depression in the general population (Linn et al 1985, WHO 2000).

5.3.2 Additional Instruments used for this analysis

Information from instruments assessing a number of outcome measures was used. Again full details of the instruments are available in Appendix B but are summarised here.

Positive, negative and general psychopathology symptoms were measured by the PANSS and their summary scores were used.

The overall functioning of participants was assessed using the Global Assessment of Functioning (GAF) (APA 1994) scale. In the GAF, detailed descriptions act as anchor points and mental status and social functioning are deliberately conflated. Scores range from 1-100 with higher scores indicating better functioning.

The Quality of Life Interview (QOLI) (Lehman 1983) was used to assess quality of life (QOL). The QOLI is interviewer-administered, has good

psychometric properties (Lehman 1993, Dickerson et al 1997), and has been extensively used internationally. It assesses subjective and objective QOL but only the subjective satisfaction with life in general component was used for this analysis. Respondents are asked to rate their level of satisfaction with life in general at the start of the assessment and then at the end on a 7-point Likert Scale where 1 equates to *terrible* and 7 to *delighted*. The mean of these two scores was used as a broad measure of subjective quality of life, consistent with many other studies (Vandiver 1998, Huppert et al 2001, Nadalat et al 2005).

Four employment status variables were coded from the Quality of Life Interview data, as described in Chapter 4. These were employment throughout the two year period, employment at baseline with subsequent unemployment, unemployment throughout and unemployment at baseline with subsequent employment.

Depression was assessed using the Calgary Depression Scale for Schizophrenia (CDSS) (Addington et al 1990). The summary score from the CDSS ranges between 0-27. A score of 6 or more was used to indicate depression as suggested by Addington et al (1996). This cut-off has a specificity of 77% and a sensitivity of 92% to detect a major depressive episode (Addington et al 1993). Thus the output data from the CDSS was used to code whether a participant was depressed or not using this cut-off.

5.3.3 Analysis

SPSS (version 12) was used to carry out logistic regression modelling for categorical outcome variables and multiple linear regression for continuous outcome variables. Separate analyses were conducted for each of the outcomes measures. Thus the dependent variables were the 2 year scores for the CDSS, satisfaction with life in general, GAF, and PANSS positive symptoms, negative symptoms and general psychopathology. The potential explanatory variables were being unemployed throughout follow-up, employed

throughout follow-up, getting a job and losing a job and the baseline scores on the relevant outcome measures. For example in the case of the dependent variable PANSS positive symptoms at 2 years the explanatory variables were the four different employment status variables described above and the PANSS positive symptoms at baseline.

No adjustment was made for any other variables partly because of the preliminary nature of the current analysis. Also the most powerful predictor of an outcome measure at 2 years was likely to be the scores on the measure at baseline, and this was adjusted for.

5.4 Results

Table 16 summarizes the results of the regression analyses. As expected GAF score, life in general satisfaction score, PANSS sub-scores and CDSS depression scores at baseline all significantly explained their own variance at follow-up. Being employed throughout the two year period was significantly correlated with having a higher GAF score, better subjective quality of life, lower general psychopathology and positive symptoms scores and reduced the odds of being depressed at 2 years, with adjustment for baseline. Employment status did not explain any of the variance in negative symptom scores at 2 years. Obtaining work over the period of follow-up also significantly predicted lower general psychopathology and positive symptoms scores at 2 years. Losing a job did not have an independent effect on any of the outcome measures.

Table 16: The effects of employment status on other outcomes

Variable	Mean difference (95% CI)	Beta standardized	P value	Adjusted R square
GAF scores				
Got a job	3.36 (0.71 to 6.01)	0.08	0.013	0.31
Employed throughout	4.50 (1.63 to 7.38)	0.09	0.002	
GAF baseline	0.56 (0.50 to 0.62)	0.54	<0.0001	
Quality of Life				
<i>Life in General score</i>				0.21
Employed throughout	0.34 (0.10 to 0.57)	0.09	0.005	
Life in general baseline	0.43 (0.37 to 0.49)	0.44	<0.0001	
PANSS symptom sub scores				
<i>General Psychopathology</i>				0.34
Got a job	-1.46 (-2.90 to -0.22)	-0.06	0.047	
Employed throughout	-1.90 (-3.44 to -3.64)	-0.07	0.015	
General Psychopathology baseline	0.54 (0.49 to 0.60)	0.57	<0.0001	0.43
<i>Negative Symptoms</i>				
Negative symptoms at baseline	0.64 (0.59 to 0.70)	0.66	<0.0001	0.27
<i>Positive Symptoms</i>				
Got a job	-0.91 (-1.78 to -0.03)	-0.06	0.043	
Employed throughout	-1.35 (-2.29 to -0.41)	-0.09	0.005	<0.0001
Positive symptoms at baseline	0.50 (0.44 to 0.56)	0.51	<0.0001	
	Odds ratio (95% confidence interval)		P-value	Nagelkerke R Square
Depression				
Employed throughout	0.25 (0.09 to 0.73)		0.011	0.181
Depression baseline	7.04 (4.55 to 10.89)		<0.001	

5.5 Discussion

This is an initial exploratory analysis of whether employment status has an effect on other outcomes in people with schizophrenia, based on 2 year cohort data.

5.5.1 Overall functioning

Continuous employment was correlated with better overall functioning at 2 years after controlling for baseline GAF score, suggesting that working is independently associated with a possible global effect on an individual's performance. Obtaining work over the two years was also independently associated with higher GAF scores at the final assessment. This suggests that the relationship between employment and GAF scores is reasonably robust and secondly indicates that working may generalize to better overall levels of functioning. Given that occupational functioning is partly used to anchor scoring on the GAF it is unsurprising that the two were correlated in this analysis, although no such relationship was found in a recent review of individual level correlates of employment (Michon et al 2005).

5.5.2 Subjective Quality of Life

Working was described as integral to a good quality of life in a qualitative study of the views of people with schizophrenia (Angermeyer et al 1999). In this quantitative analysis also, maintaining employment over two years was correlated with higher life in general satisfaction scores. The beta values however were small, indicating that the differences in subjective quality of life between those who maintained employment compared to others may not be clinically meaningful. Working has been associated with a higher subjective quality of life in a number of previous prospective studies also (Bond et al 2001b, Addington et al 2003).

Interestingly merely the acquisition of a job was not significantly associated with better quality of life at 2 years, implying that there may be a considerable

time lag after getting a job until an effect on quality of life materialises. It appears that it is maintaining employment and not merely exposure to a work role that is important. There may be a number of possible explanations for this pattern. For the general population it has been suggested that it is the economic security associated with working that improves quality of life and not participation in the labour force per se (Anderson 2002). This may be the case for people with schizophrenia also and explain why maintaining employment but not getting a job was correlated with better quality of life.

Another conceivable explanation is that for people with schizophrenia the act of getting and starting a job is fraught with dilemmas, a situation unlikely to result in better QOL. There may be anxiety about how financially worthwhile employment will be compared to living on benefits or about job security and also concern that working may damage mental health (Garske & Stewart 1999). It is likely that after a period of time in employment these concerns become less, and there is a greater sense of security and confidence in the work role. This shift in thinking and role adjustment is likely to take time but may explain why it is maintaining employment but not exposure to work that is associated with better subjective QOL.

5.5.3 PANSS symptom sub-scores

Maintaining employment over the 2 year period was correlated with lower scores on the positive and general psychopathology symptom subscales, suggesting that continuous work may be linked to a reduction of these symptoms. Reverse causality is of course a distinct possibility also; that is people with lower symptoms scores may have been more able to maintain employment over time. However people who were unemployed at baseline but who then obtained work also had significantly lower symptoms scores by two years after controlling for baseline symptoms levels, adding at least a degree of plausibility to the argument that working may possibly result in lower symptom levels.

If it is the case that employment can lead to a reduction in symptoms prospectively, the underlying mechanism to this process is unclear. One possible explanation comes from a qualitative study which investigated the attitudes and coping skills of people with schizophrenia to understand the factors associated with successfully gaining and maintaining work (Cunningham et al 2000). People who were employed tended to describe their illness as a small part of who they were, had better coping skills generally and had developed better illness management strategies. It is possible that utilizing these illness management skills such as developing a mindset of taking 1 day at a time, distraction and relaxation as described by Cunningham et al (2000) results in a diminution of symptoms such as anxiety and even the misinterpretations linked to early delusion formation. Indeed some of these strategies may underlie the effectiveness of cognitive behavioral therapy for a range of symptoms.

5.5.4 Depression

Being employed throughout the period of follow up reduced the odds of depression at 2 years after controlling for baseline CDSS scores. Surprisingly only very little evidence exists in the literature regarding any link between clinical depression and employment in people with schizophrenia. Some studies report a correlation between less depressive symptoms and work (Resnick et al 2004), whilst others either report no association (Rosenheck et al 2006) or an association which appears weaker than for other functional outcomes (Conley et al 2007). The association between depression and employment was not tested using the EuroSC cross-sectional dataset although higher PANSS general psychopathology scores that include a measure of depression did reduce the odds of working. The results of this analysis indicate that maintained employment possibly protects against future depression, although again it is difficult to be sure of the causal direction.

5.5.5 Limitations

The limitations of the EuroSC study design and methodology have been discussed in Chapter 3.

The analyses in this chapter were exploratory and all potential explanatory variables relevant to the outcome measures of interest were not included in the regression modelling. Therefore the possibility exists that the associations between employment and GAF, quality of life, PANSS scores and depression could be rendered non-significant or attenuated if other explanatory variables were to be included in the regression models.

There is a degree of uncertainty in the direction of causality within the associations found from the analyses in this chapter. Thus taking the association between employment and a reduction in psychotic symptoms as an example, there is still a question about whether people got a job because their symptoms improved or their symptoms improved because they obtained employment. The PANSS positive summary score at baseline was included as an explanatory variable so that inferences on causality could potentially be made, but the possibility remains that people obtained work because their symptoms became less severe.

It is possible to be more confident about the direction of causation in the finding that maintained employment is correlated with better quality of life at 2 years. This is because it does not seem theoretically likely that a greater satisfaction with life would necessarily lead to employment.

5.6 Summary

The analyses in this chapter lend support to previous studies in suggesting that employment may be linked to better subjective quality of life, general levels of functioning, lower general psychopathology and positive symptoms scores and a reduction in the odds of depression. There is, however, an

important caveat regarding the extent to which the direction of causality can be ascertained from this and other analyses.

Chapter 6

Views and experiences of employment among people with severe mental illness: a qualitative descriptive study

6.1 Introduction

Thus far in this thesis I have used statistical analyses of a large epidemiological sample of people with schizophrenia in order to understand the rates, correlates and barriers to working that people face. In this Chapter I use an alternative type of methodology, a qualitative analysis to explore the same subject. I address aim 5 of this thesis by interviewing a small sample of people in considerable detail regarding their experiences and views about working and then thematically analyse these discussions. This enables an additional and complementary understanding of the factors that may influence the rate of employment in people with schizophrenia.

The experiences of service users with schizophrenia of trying to obtain and keep employment, as well as the perceived barriers to working have been the focus of only a limited number of investigations. Studies carried out to date, the results of which have been summarized in Chapter 2, have usually used questionnaires and these are unlikely to capture the full complexity of participants' views and experiences related to work. In addition many studies have interviewed people who form diagnostically heterogeneous samples. People with SMI have poorer occupational outcomes than those with other psychiatric problems (Gureje et al 2002, Bland et al 1998) and may therefore have different experiences and opinions. Also little has been written about what people with schizophrenia think would enable them to work.

The study described in this chapter was the first of the studies presented in this thesis to be completed.

6.2 Aims

This study aimed to examine the views and experiences of a purposive sample of fifteen patients with SMI on the following themes:

- The advantages and disadvantages of working from service users' perspectives
- The ways in which illness affects the ability to work
- Experiences of looking for work and perceived barriers to finding and keeping work.
- Opinions on current local service provision.

6.3 Method

A qualitative method, based on thematic analysis of transcripts from semi-structured interviews was selected in order to allow detailed exploration of participants' views and experiences. Also this method avoided imposing a fixed set of categories on complex subject matter.

6.3.1 Sampling Frame

Approval was obtained from the Camden and Islington local research ethics committee. For the purposes of the study, severe mental illness (SMI) was defined as an established diagnosis of schizophrenia, schizoaffective disorder or bipolar affective disorder, a somewhat narrower definition than often used. Four care co-ordinators in an inner city community mental health team (CMHT) in North London were asked to identify patients on their caseload who met these diagnostic criteria and were not in hospital. A total of 52 names were provided and consecutively numbered 1 to 52 to code their identity.

A purposive sampling method was used in order to ensure that a full range of service user characteristics and experiences was represented. Thus before

recruitment it was determined that the sample should include at least 6 males and 6 females, at least 5 unemployed participants and at least 5 who were currently employed (including competitive and voluntary employment). In addition at least 6 people with schizophrenia and 6 with bipolar affective disorder (BPAD) were to be selected. People with psychotic depression were excluded as previous research (Bacani-Oropilla et al 1991) suggests that this group have different occupational functioning to those with schizophrenia and BPAD.

Participants were selected from groups of patients with particular characteristics (e.g. diagnosis of schizophrenia, employed). If a potential participant refused to take part in the study, another was recruited until the required number had been interviewed. Given the high level of morbidity required for care coordinator allocation in inner city CMHTs, only a very small number were employed in the initial participant list. A further five participants who were employed were therefore recruited from the out patient list by asking clinic doctors to identify people under their care who were working. People who were primarily seen in outpatients tended to be clinically better than people requiring a care coordinator.

Potential participants were initially contacted by phone, told about the study and asked if they would be willing to meet in person to discuss it further. If a telephone number was not available or they were not contactable by phone, a letter was sent inviting them to participate.

6.3.2 The interview

The qualitative interview guide was developed in collaboration with an occupational therapist (OT) with the study aims in mind. Previous literature on the attitudes to work of people with SMI was drawn upon to decide which areas for discussion were to be included in the interview. The wording of initial questions in the guide was decided by agreement between the OT and myself. In order to ensure content validity the interview was piloted with three potential participants from the patient list of the CMHT. These people were

unemployed and not actively looking for work, unemployed and applying for a job and employed in a voluntary capacity. In response to their comments, the interview guide was modified and refined. The final semi-structured interview used is shown in Appendix C.

Participants were told that responses were confidential and their identity would be concealed in the final analysis. The interview schedule was used for exploration as a starting point but the respondents determined interview content (design flexibility), allowing them to introduce relevant themes not included in the initial interview guide. Although the primary interest was in exploring views and experiences related to paid employment, the scope of participants' responses often included discussion of work as defined more broadly rather than only paid employment. The interviews were recorded on audiotape and transcribed by secretarial support staff. I compared a sample of the transcripts with the recordings on tape and these were found to be accurate.

Demographic and clinical details collected included age, gender, diagnosis, current employment status and previous work record (pre and post-illness onset). One interview was carried out in the person's home but all others at the community mental health centre.

6.3.3 Analysis

The type of qualitative analysis chosen was a thematic examination of the content of the interviews, consistent with the techniques of other researchers investigating attitudes and views (Gardner & Chapple 1999). The thematic analysis of the transcripts was carried out with the aid of QSR-NUD-ist Classic (a computer programme which supports qualitative data coding and analysis) to identify beliefs, attitudes and experiences. The interpretative process described here was decided on before the start of the analysis.

All the transcripts were initially read and basic demographic details recorded. Repetitive reading of the transcripts enabled a coding structure to be

developed, with the questions asked during the interview being used as a starting point. In this way text within the transcripts was coded into themes. Novel ideas not specifically asked about in the interview were also identified whilst initially reading the transcripts. These themes were also assigned codes and then specifically searched for during further reading of the data. The text within each code was then re-read to check for the validity of the coding and to see if further themes could be identified.

6.3.4 Validity and Reliability

A lack of reliability has been described as a criticism of qualitative research (Mays & Pope 1995). In order to check on and improve the reliability and validity of the coding structure a consultant psychiatrist colleague and supervisor (SJ) independently coded four randomly selected transcripts. Because the level of text coding agreement between the coders was found to be less than 75% the definitions of some of the themes were refined and the coding framework was further developed by the addition of new themes. All the transcripts were then re-coded using the new coding framework. SJ independently coded two further transcripts to recheck coding reliability. This was found to be satisfactory at 80%. The remaining discrepancies were largely text-coding omissions as opposed to text coding differences.

6.3.5 The setting of the study

This study was carried out in Islington in North London, an area with considerable deprivation, a population of approximately 176000 and an unemployment rate in the general population of 9.1% (Office of Population Censuses and Surveys (OPCS) 2001). Local specialist employment services for people with mental illness are scarce and are mainly provided by the voluntary sector. Available services include the *Employment Project* (provided by a national voluntary sector organisation which campaigns for and provides services for the mentally ill), which assesses work skills and provides training on how to get work. There is also a day centre, which provides some vocational rehabilitation. Supported employment is limited and there is no

substantial scheme aimed at securing competitive employment for service users. There is a high quality benefits advice service provided by *Islington Peoples Rights*, a voluntary sector organisation that works closely with NHS mental health services.

6.4 Results

In describing the results, the number of interviews in which a particular theme was identified is reported at times. This is intended to indicate the relative prominence of particular ideas and views in this sample. These figures cannot of course be equated with frequencies reported from a statistically representative group of people with SMI.

6.4.1 Sample socio-demographic details

The socio-demographic details of the final sample are shown in table 17. Everyone in the sample had done some form of work in the past. Nine people selected did not participate. Two of these were uncontactable and seven refused.

6.4.2 Desirability of working

Nearly all of the interviewees (13 out of 15) said that they wanted to work. Two of the participants, both of whom had schizophrenia felt they could not work because they were not well enough. One of these said: *"I would like to work if I didn't have mental health problems. I have a lot of insurmountable mental health problems that get in the way"*.

Table 17: Socio-demographic details of participants

Characteristic	Number of participants (N = 15)
<i>Gender</i>	
Men	8
Women	7
<i>Diagnosis</i>	
Schizophrenia	8
Bipolar Affective Disorder	7
<i>Age</i>	
18-40 years	9
Over 40	6
<i>Ethnicity</i>	
White UK	10
Greek	1
Italian	1
Turkish	1
Black African	1
Argentinean	1
<i>Employment status</i>	
Unemployed	8
Competitive employment	3
Voluntary or sheltered employment	4
<i>Worked pre-illness and post illness onset</i>	14

Although people almost always said they wished to work, many (6) wished to work only part-time as they felt they could not cope with starting full-time work directly from unemployment. An unemployed man with schizophrenia said “*I would prefer to do part time jobs for a few years to see if I can handle that. It’s a lot easier to do.*”. When asked why, he said “*basically to see the stress levels aren’t too high.*” However some respondents reported that they would not consider part-time work because the pay would not outweigh the loss of benefit entitlement.

The participants gave a number of reasons why working would be advantageous to them. The commonest was financial gain. This was not solely related to the desire to be wealthier but also to increase a sense of autonomy and independence by ceasing to rely on benefits. Participants believed it would give them more control over their lives. For example an employed woman with BPAD said “*the advantage for me in work is the sense of self esteem...the fact that I would be earning my own money, making decisions about my life*”. Participants talked about work giving them a clear role and empowering them to become part of mainstream society once again. For example a man with schizophrenia said, “*it would certainly help to give me more of a purpose to life. On the mental health scene if all you do is visit day centres, it means you’re just drifting. It’s not like having a career or a job*”.

Four participants, 3 of whom were employed, said that working was good for their mental health. An older employed man said “*... I mean I’d hazard that yes, it’s extremely stabilising. It’s a form of creative Lithium if you like*”. There were no other obvious differences by employment status. Other advantages of work cited were opportunities to meet other people and provision of daytime structure.

After the initial strong assurances of wanting to work and describing its advantages, many participants went on to express substantial doubts. These ranged from a fear of letting people down to doubts about their physical ability

to work. Concern about benefit entitlements if they were working was common in the sample (7), but less so among the employed (2/7). A woman with BPAD said *"....I think the benefit system does work against people with mental health problems actually getting back to work"*. There seemed to be a good deal of uncertainty about the relationship between earnings and loss of benefits and many people believed that they would almost certainly lose all their benefits if they did any paid work, even if this was as little as a few hours a week.

A number of people expressed their concern over whether in reality they would be financially better off and seemed to be well aware of the benefits trap. An unemployed man with schizophrenia said, *"I don't think it would make a lot of difference...I'd have to pay council tax...I'd have to pay fares. I don't think I would be better off financially. I mean people just say I should work but they don't think of the consequences"*.

The nature of the work that they might be required to do also seemed important and a few participants, often those whose level of social functioning appeared generally high, expressed reservations about having to work in an unskilled or unsatisfying job. For example a woman with BPAD said *"something that was interesting, of value, that I felt appreciated in...I mean basically I'm pretty sure I could get a job stacking shelves in Safeways or whatever but I don't want to do that"*. Some respondents suggested they had found alternative activities from which they gained some of the satisfaction they might get from work. For example a woman with BPAD said, *"I consider I'm already working. I'm a mother, I've been engaged in promoting good practices in mental health....I'm a regular member of the day centre.....so I'm constantly engaged in doing things"*.

6.4.3 Mental health problems and effects on work

When asked how their mental health problems might affect their ability to work most participants (12) said that symptoms of their mental illness, primarily affective or psychotic ones, would interfere with functioning at work. A woman

with schizophrenia said, *"the voices... lack of concentration"*. She went on to say, *"I need help with the voices. It would help if I didn't hear them anymore"*. Two participants also thought concentration or memory problems would affect their ability to function at work.

Adhering to medication whilst working was seen as problematic by many participants because of side effects (6) or the practicalities of being able to take the medication during work time (2). An unemployed man with schizophrenia said *"now I have to have an injection every two weeks... do you tell your prospective employer that you suffer from mental illness and that you want time off to go have your injection or do you make some excuse every time?...it's a bit of a quandary really"*. A minority (4) talked about problems getting up in the morning that made it difficult for them to work.

Concern that working might lead to a relapse of their mental illness was very common (5 unemployed and 4 employed). A few had experienced this while others saw it as a risk. A typical comment was *"....could be a stressful job and I won't be able to cope with it and I'd end up having another breakdown."*. Many talked about their experiences whilst at work and how their mental health problems had affected these. An unemployed woman with schizophrenia reported, *"my face is always red, I look very anxious. I used to work in a shop and realised I looked very anxious, so I stopped working in the shop"*. A man with BPAD said, *"...other times I've probably gone over the top in (work). I remember writing down dozens and dozens of comments, overflowing"*. When asked if his employers were supportive he said, *"I just left and gave up my job...and that damaged my career irreparably"*.

When people had stopped work due to their illness they had nearly always left of their own accord rather than being dismissed. This had often happened at a time when their illness was becoming worse but they did not feel able to talk openly to their employers about it. They either resigned or simply did not turn up for work because of a behavioural disturbance or being admitted to hospital. In a typical comment an unemployed woman with schizophrenia said

“Well that is why I left telecoms, because I walked.... Well I thought people were talking about me and then things started going fast in my head”.

However pressure from employers and colleagues may have contributed to these decisions to leave work. A number of people described feeling discriminated against at work when they became ill, and also on their return to work. They felt that this was often disguised; for example being asked to move to a location to which it was not so easy to commute or being asked to take a demotion. A man with BPAD who returned to work after a manic episode but subsequently took medical retirement said, *“well what happened was, I went back and I felt a bit ostracised. People weren’t as friendly as they were before. I don’t know why”*. Only three participants had been dismissed from their job. This was because their employers believed they could not do the job any longer due to their mental health problems. An unemployed woman with schizophrenia said, *“after I went into hospital, I started again and then they said I must not work in this place...I get tired very quickly and nobody helped me....I started making simple mistakes. Before I never done these things”*

Despite these problems several people described instances of obtaining work or keeping a job despite psychiatric illness. Participants frequently talked about their employers knowing about their mental health problems and therefore providing them with support at work as the key to enabling them to continue. For example a 24-year-old employed man with schizophrenia said *“and they said that if it didn’t increase (work-rate) they wouldn’t be extending my application for a full-time position. But I told her about my schizophrenia and afterwards she said, well I’ll scrub off the statement about not keeping you on, but if you can make those improvements”*.

6.4.4 Attitudes to employers and the perceived beliefs of employers

Stigma was frequently discussed when people talked about their prospects of finding work. Approximately two thirds of the participants said they wouldn’t tell potential employers about their mental health problems because they feared discrimination. A 35-year-old man with schizophrenia said, *“I don’t think*

you'd get a foot in through the door that way. You wouldn't get taken on in the first place if you told them you had a big mental history."

Even though most people would not tell a potential employer about their mental health problem, about a third thought their situation would be better if the employer was aware of and accepted it. This belief co-existed with believing that it was important to hide mental health problems from employers initially so as to get work. For example when asked if he would disclose his illness during the selection process a man with schizophrenia said, *"Not if I wanted the job but then that would increase my likelihood of going nuts, because I wouldn't let anyone get too close or meet my friends who did know I have a mental health problem"*. The most commonly cited reason for telling an employer was so that they would be forewarned that the person might become ill and that this might affect their performance at the job.

The belief that employers would prefer not to employ people with mental health problems was almost universal. Most people (11) believed that employers would worry about their functional ability to do the job as well as about risks. A 35-year-old man with schizophrenia said *"it's a risk to the employer and they might go mad one day with a big knife and attack someone. Or they might just not be as efficient as someone who hasn't got mental health problems"*. Participants thought that as well as the risk of violence, employers would be concerned about the number of sick days taken and disruption to the work force. The three people who were competitively employed had not told their employers about their illness at interview.

Interestingly, a significant minority of participants (6) thought that employers were justified in their concerns and in their reluctance to employ people with SMI. A young man with schizophrenia who was employed commented, *"just say there's two different people. One with mental problems and one's fine. The one who's fine can be told I need you to stack four shelves today...whereas this one he can do it but he still needs support...I think he'd be a bit of a burden on the employers"*. Some participants had self-

stigmatising views of those with SMI with regards to work. A woman with BPAD said *“in all seriousness I’m not sure unless you had a vacancy you couldn’t fill you’d take on someone with mental health problems anyway”*.

6.4.5 Getting a job

Only a minority of participants was currently actively seeking employment. Seven participants talked about advice regarding work received from professionals or the lack of it. Those over 40 years of age seemed more likely to have been advised against working or against more demanding employment. In talking about her struggles to lead a normal life a woman with BPAD reported *“one psychiatrist told me I’d only ever do menial work, that I’d never be fit to do anything that required responsibility. I named her Dr Murderoch”*. Two participants under 40 years said that no one had mentioned work to them or explained what services were available.

When asked how they might go about finding a job, people mentioned three strategies: attending the local Employment Project, trying to find work themselves by looking through adverts or going to the job centre. The latter was perceived as the least effective option. For example an unemployed woman with BPAD said *“...I think they’d push me into a job that I didn’t think I’d be able to do... I find going to the job centre the most soul-destroying experience. Then again everyone would.”* The people who used the Employment Project found the service friendly, although generally unsuccessful in helping them to obtain competitive employment.

The majority of participants had done some form of voluntary work in their lives. Many of them discussed this type of work positively as increasing their self-esteem and providing an environment where they felt supported and could work despite their mental health problems. However a few people said that they would never do voluntary work because of the lack of financial remuneration. The majority believed that voluntary work did not prepare you for competitive employment. A man with BPAD described the positive aspects and problems with voluntary work: *“I just saw it as voluntary work, I didn’t*

really see it as preparation for a full-time job. The discipline of getting up in the morning is a good idea...but all other aspects doesn't.... because you can do what you like, you can either work or you don't."

Most thought that not enough specialist employment services were currently available. People identified a range of functions that a dedicated service might have. These included help with filling out application forms and curriculum vitas, support and advice on interview skills, and the provision of references. Three participants said that such a service should provide a list of jobs that were available and might be suitable for them. Furthermore they wanted these jobs to be ones in which their mental health problems were known. An employed man with schizophrenia said *"I think they should have a lot more links with employers. It would be nice to have a list of employers who have been to a week's training on mental health issues and understand the ins and outs. and that you don't have to start with a blank slate."*

6.5 Discussion

6.5.1 Working

As in previous studies (MIND 1993, Secker et al 2001), when asked for a yes or no response nearly everyone said they wanted to work. However this was frequently followed by the expression of substantial doubts, and these initial firm assurances may to some extent reflect the social desirability of work. These initial statements about wanting to work could also be described as public accounts (Pope and Mays 1995), behind which a set of rather more complex and contradictory private accounts emerged on more detailed exploration.

That these doubts about working were important in practice seems to be confirmed by the finding that very few of the unemployed participants were actively seeking work. This gap between expressing an interest in employment and actively seeking it is important as there is evidence from the general population as well as in those with SMI (Tano 1991, Mueser et al

2001) that people who are searching for employment are much more likely to be working in the future.

Based on exploration of the views and experiences of the long-term unemployed in the general population, Jahoda (1981, 1982) has identified a range of latent functions of work. The loss of these, as well as of work's manifest function as a source of financial reward, is important in understanding unemployment's psychological and social effects on individuals.

According to Jahoda, latent functions of work include the imposition of a time structure, participation in a collective purpose and the enlargement of the scope of activities into areas less emotionally charged than family life. These themes, especially the first two, also emerged from the interviews conducted for this study. For example working was seen to have many potential advantages including social contact, daytime structure and self-esteem as well as financial gain (although this was later questioned). However, the study participants did not see paid work as the only source of these, and a functional response to long term unemployment for some people with SMI may be to establish other social roles which yield some of the latent functions of paid work. Such roles may be as a carer, an advocate or working in the voluntary sector. Thus some people with SMI may feel that looking for paid employment may not currently be the best option given their level of morbidity, discrimination and the other barriers they face and the possibility of having to do very menial work.

Previous unsuccessful experiences of seeking and trying to retain jobs may also strongly discourage active job seeking. Participants' accounts of previous experience of working suggested that they had generally left of their own accord into unemployment or entered acute psychiatric care. This is somewhat different from some US evidence (Becker et al 1998) in which more than 50% of job terminations were due to the person being sacked, although this sample was made up of assertive community treatment clients.

In the current study sample, discrimination seemed to be felt most potently when people tried to return to work. If this pattern is prevalent, the issues in relation to UK laws on disability discrimination are quite complex in that people are not actually being dismissed, which might well be illegal. There appears to be a rather more complex social process on return to work, which results in people feeling unwelcome. These findings corroborated those reported by a German study on stigma and SMI (Schulze & Angermeyer 2003) suggesting that people with schizophrenia experience a denial of their skills and criticism on their return to work after an illness episode.

6.5.2 Barriers to working

Patients face external and internal barriers, which are likely to interact. These barriers are now discussed in turn.

6.5.2.1 External (Societal)

At some point most participants talked about enacted stigma (a mark of disgrace or discredit that marks a person out from others) as an important determinant of their chances in the job market, and there is some evidence for this from previous studies (Crisp et al 2000, Manning and White 1995). In particular participants believed that employers were worried about a number of risks including violence, extensive sick leave and the potential for them to be a disruptive influence in the work environment including to their colleagues. Because of this discrimination, people face a difficult dilemma in that they believe they must conceal their illness to get a job, but that doing so seriously jeopardises their chances of keeping it.

In line with previous research (Rinaldi and Hill 2000) loss of benefits was seen as a major reason not to return to work. The extent of the monetary disincentive to work is large. For example in 2003, a 25 year old man with paranoid schizophrenia who worked for 3 years before he became ill, but had been unemployed for 2 years and was living in a 1 bedroom council flat in Islington would have been entitled to a little under £15000 in Department of

Health and Social Services (DHSS) benefits. Around £9000 of this is as disposable income (personal communication from Islington Peoples Rights 2003).

Assuming a patient worked a 40-hour week on the minimum wage of £4.20 (2003) they would have received about £9000 a year in 2003. Therefore the reservation wage (Berndt 1991) (the wage at which working becomes economically viable) for those with SMI is high.

It would seem that the unemployment and “benefit trap” for people with mental illness is more significant than for the general population. This is primarily because the more disabled a person is, the more benefits they are entitled to and therefore the higher the disincentive to work (Turton 2001), although the gradual increase in the minimum wage may have had the effect of making work more financially viable. The trap is most potent for people who wish to do paid part-time work, as the majority of people in this sample did and this may be the biggest deterrent when considering the move from unemployment. The fear of having difficulty in getting benefits reinstated if an attempt to start work is unsuccessful may be a further limiting factor.

Understandably people reported they would only work if their income were more than their total benefits entitlement. The reported lack of easily accessible information about losing benefits and employment may be partly responsible for the level of concern expressed about this.

6.5.2.2 Internal (individual)

The internal barriers consist of people's attitudes and beliefs. It is likely that they are reflections of low self-esteem, a loss of motivation, worries, past experience and an acceptance of and adaptation to unemployment. They are similar to the attitudes expressed by the long term unemployed in the general population (Blumenberg 2002).

A minority of participants said they were not well enough to work, although a greater number felt they were well enough to work on a part-time basis only. In addition many people said that working might lead them to become unwell. These fears primarily expressed by those who were unemployed corroborate previous work (Van Dongen 1996), suggesting that those who are unemployed are more fearful of working than those who are actually employed. The concerns that people expressed with regards to the side effects and practicalities of taking medication may be an impediment to work that could be addressed by clinicians.

Although participants complained about discrimination from employers, some believed that the employers were justified in their concerns. Many people's comments suggested that they accepted these attitudes with a degree of fatalism and felt that there were not good enough reasons for employers to be challenged about them. A number of people also talked in a way that was very self-stigmatising with regard to work.

There is an increasing literature on the effects of self-stigmatisation on people with mental illness, suggesting potentially harmful effects on self-esteem and self-efficacy (Corrigan & Watson 2002, Watson et al 2007). These consequences may be particularly important given that the belief that one is not as able or employable as someone without mental health problems is likely to act as a severe disadvantage in the labour market.

Even though UK legislation requires employers not to discriminate against the disabled and to make reasonable adjustments to allow people to sustain work, many people in the study sample did not appear to feel they had a right to support in getting access to the roles and experiences that others in society have and to the help they require to be able to realise their potential.

6.5.3 Current service provision

Advice regarding work may reflect mental health professionals' views about the importance and feasibility of employment for those with SMI. Received

work advice seemed to have been more stigmatising for the older (40 plus) age group than for younger people. Although the interview guide did not include a direct question about advice regarding employment from mental health professionals, some participants complained about the lack of it. This also might indicate a view amongst mental health professionals either that it is not their role to advise on employment or that employment is not feasible for people with SMI. Indeed vocational services do not tend to be included in care plans for people with schizophrenia (Lehman et al 1998). As well as hindering people's progress back to employment these attitudes may also reinforce low self-esteem and hopelessness with regards to work.

Attending a specialist employment service for those with mental illness was seen as the most helpful source of assistance in getting back to work. The main criticism of current service provision, however, was that it often directed people into unpaid rather than open employment. Although voluntary work was seen as therapeutic, the majority reported that it did not prepare them for competitive employment, reflecting the conclusions from research into the IPS service model (Drake et al 1999a). However this does not mean that voluntary work has no useful functions in that it clearly provided many of the latent functions of work for some of the people interviewed.

Given the rather limited level of service provision available in the study catchment area, it was unsurprising that participants reported that not enough help was offered in relation to employment. As well as wanting practical help in the process of finding work they also wanted services to have links with sympathetic employers and in some ways to be advocates for them with those employers, perhaps helping to resolve their dilemma regarding the conflicting advantages and disadvantages of telling employers about their illness. It appeared therefore that they wanted at least some of the elements proposed in the IPS model of vocational assistance, which is now supported by European (Burns et al 2007) as well as US (Crowther et al 2001) evidence.

6.5.4 Limitations of the study

Seven people refused to participate in the study. Although a reason for refusal was not required, several mentioned that they did not want to be recorded on audiotape, despite assurances regarding the security and confidentiality of this. It may be that those who agreed to be interviewed had particularly strong opinions about employment. However, from interviewer observation there was a wide range of illness severity and strength of opinion in the participants. No one interviewed talked about working in the unofficial labour market. It is possible that some of those who refused to participate in the study fell into this group.

The respondents were aware that the interviewer was a psychiatrist. This may have led to socially desirable answers, although the doubts that people expressed about working would temper this view.

Although the participants were selected to represent a full range of characteristics and experiences among people with SMI and therefore to some extent the results will be generalisable, the sample size is small and entirely drawn from a single inner city area. Opinions and attitudes may well be different in areas, which are less socially deprived or provide different employment services.

6.6 Summary

People with SMI expressed a range of potential benefits to working. They also described a number of serious doubts, and these may go some way in explaining why many people with schizophrenia do not appear to be actively looking for work. Participants' views suggest there are individual and societal barriers to working. Respondents did not believe there were enough helpful employment services available to help them.

Chapter 7

Staff attitudes to the employment of people with psychosis

7.1 Introduction

Clinicians' attitudes to mental health problems are important given that they determine information gathered, needs identified and interventions offered to patients (Conning and Rowland 1995). A striking absence in the current literature is a systematic exploration of staff attitudes towards the employment of people with schizophrenia. A limited amount of evidence and expert opinion (Rinaldi & Hill 2000, Bond et al 2001a, Grove and Membrey 2005, Goldberg et al 2005), suggests that these attitudes may be generally negative and unhelpful. Specifically in the context of the UK, little information is available about the views of clinicians working in community mental health teams, although they provide the majority of care to people with schizophrenia and may be best placed to identify needs for advice and help with employment issues.

Thus in this chapter I report a study which addresses Aim 6 of this thesis. Whilst the previous chapter investigates patients' views about working, the study in this chapter augments this knowledge by examining the perspectives of clinicians on the employment of people with psychosis.

7.2 Aim

- To survey the attitudes of mental health professionals on the employment of people with psychosis and the main impediments to helping their clients work.

7.3 Method

This study is a questionnaire survey of clinicians working in 9 community mental health teams in North London.

7.3.1 Study site

The study participants were mental health professionals employed by the Camden and Islington Mental Health and Social Care Trust, North London between 2004-2006. As described above in section 6.3.5, this NHS trust provides mental health services for a geographical area with considerable socio-economic deprivation with a population of approximately 374000 (OPCS 2001). The majority of people on the caseloads of CMHT workers have a psychotic disorder and the majority of these a diagnosis of schizophrenia.

The Camden and Islington Community Local Research Ethics Committee gave ethical approval for the study. All mental health professionals from 9 Community Mental Health Teams for adults of working age and the Early Intervention Team for people with psychosis were asked to participate in the study. Informed consent was obtained and participants were told that their responses would be analysed in an anonymous manner.

7.3.2 Recruitment

The team managers were initially contacted to describe the study and asked to discuss participation with their staff. On agreement, a list of all the names of the staff in the team was obtained and each name linked with a number used on the questionnaires. This was done so that responses were confidential but that it was possible to tell who had not returned a completed questionnaire so that reminders could be sent.

At a pre-arranged time the CMHT was visited, normally after the weekly multi-disciplinary meeting. A standardised short verbal introduction to the study was

provided and an information sheet given. Informed consent was obtained and then the questionnaire given to the staff to complete. If participants did not wish to complete the questionnaire straight away, they were collected at a later date (usually a week later). If not present at the CMHT meeting, team members were contacted individually about the study by letter or phone. Non-responders were sent a written reminder asking them to complete a questionnaire a few weeks later. If they still did not respond it was assumed that they did not wish to participate in the study.

7.3.3 Questionnaire development

Searching the literature was not fruitful in finding a suitable questionnaire that had been used in previous studies and covered this area adequately. Therefore a new instrument was specifically developed for use in this study. An initial draft questionnaire was constructed with the questions designed to answer the stated aims. The content of the questionnaire was partly informed by themes identified from the qualitative study of patients' beliefs and attitudes about employment (Chapter 6). Results from previous research discussed in Chapter 2, describing clinicians' concerns and beliefs regarding the feasibility of work for people with schizophrenia, were also used as a basis for the construction of the questionnaire.

In addition potential themes were discussed with a Consultant Psychiatrist colleague and supervisor (SJ) and with a Project Manager (BB) for a service user employment programme based in Camden and Islington. BB informally obtained the opinions of service users of the employment programme concerning questions that should be included in the staff attitudes questionnaire.

Thus the draft questionnaire included items in the following areas:

- Whether people with a psychotic disorder can and do work and the types of occupations they are capable of
- The potential advantages of work and the main impediments to working that people face
- How much of a role staff believe they should have in facilitating people with a psychotic disorder to work
- How much training staff have had in employment and psychosis and how much they think is needed
- Opinions on currently available employment services and on the types of service that should be developed.
- A section at the end of the questionnaire invited respondents to add any other thoughts about the subject of employment and psychosis.

The draft questionnaire was further developed by asking for comments from 3 psychiatrists with significant research experience and was then piloted with 5 clinical staff from a CMHT to assess its face validity, clarity and acceptability. Modifications to the questionnaire were made taking their comments into account. The finished questionnaire required approximately 5 to 10 minutes to complete and is shown in Appendix D.

7.3.4 Analysis

SPSS (version 11.5) was used to carry out the analysis. Each question stem was coded as a separate variable. The responses to questions 1-3, which ask about the number of people on the clinicians' caseload that could do different types of jobs, were converted to percentages for ease of interpretation (see Appendix D). The analysis of these data was largely descriptive; the frequency of responses to the questionnaire items are reported and interpreted.

7.4 Results

7.4.1 Sample characteristics

A total of 91 mental health professionals from a potential sample of 138 completed the questionnaire, giving a response rate for the study of 66%. The demographic characteristics of the sample are shown in Table 18. Surprisingly there was only 1 occupational therapist in the sample and no nursing assistants, with the majority of respondents being community psychiatric nurses as expected.

7.4.2 Staff opinions on whether people under their care can work

Table 19 shows the responses of CMHT workers when asked their views about how many of their clients with a psychotic disorder were capable of working in particular types of job and how many were actually working. Because there was variation in the number of people with a psychotic disorder on respondent caseloads, the original responses (numerical digits) were converted into percentages to allow comparison. The total numbers from the combined caseloads (N=2374) of all respondents who were judged to be capable of working in different jobs are also presented in Table 19.

Staff believed that very few people with psychotic disorders were capable of full-time paid work and that 40% were incapable of any work. Only a small number of people were actually in any kind of employment, with the largest percentage doing part-time voluntary work. Among those thought capable of doing paid work, being a gardener was the job that staff were most likely to think patients could do, while few were considered able to be marketing manager or police cadet even if given prior training.

Table 18: Characteristics of the sample of mental health professionals

	Frequency	Percentage
Profession		
Nurse	36	39.6
Occupational therapist	1	1.1
Psychiatrist	17	18.7
Social Worker	26	28.6
Psychologist	8	8.8
Support Worker	3	3.3
Team		
CMHT	78	85.7
Early Intervention service	13	14.3
Gender		
Male	39	42.9
Female	51	56
Missing	1	1.1
	Mean (yrs) (standard deviation)	Range (yrs)
Age	40.76 (9.55)	25 to 61
Number of years qualified	13.1 (8.77)	1 to 36

Table 19: Clinicians' reports (N=87) of who is working and numbers capable of working in different types of job

	Types of job			
	Full-time	Part-time	Voluntary / Sheltered	Incapable of work
Mean % of people on individual caseloads thought capable of working (range)	11 (0-65)	19 (0-78)	29 (0-100)	39 (0-100)
Total number on combined caseloads thought capable of working (%)¹	326 (13.7%)	477 (20.1%)	733 (31.2%)	820 (34.9%)
	Full-time	Part-time only	Full-time voluntary	Part-time voluntary
Mean % of people actually working on individual caseload (range)	3 (0-38)	4 (0-27)	2 (0-40)	10 (0-100)
Total number on combined caseload working (%)¹	90 (3.8%)	98 (4.1%)	92 (3.9%)	431 (18.2%)
	Marketing manager	Computer programmer	Nursing assistant	Library assistant
Mean % of those who could manage paid work would be capable of being a (range)	15 (0-100)	30 (0-100)	34 (0-100)	54 (0-100)
Total number on combined caseload capable (%)¹	113 (14.1%)	227 (28.3%)	296 (36.9%)	399 (49.7%)
	Child minder	Sales assistant	Gardner	Police cadet
Mean % of those who could manage paid work would be capable of being a (range)	24 (0-100)	55 (0-100)	65 (0-100)	15 (0-100)
Total number on combined caseload capable (%)¹	151 (18.8%)	333 (41.5%)	486 (60.5%)	139 (17.3%)

Total combined caseload is 2374. Total number reported to be able to manage paid work is 803

¹ % of combined caseload

7.4.3 Perceived advantages and barriers to people working

Clinicians were also asked to rate the importance of a series of potential advantages of working; the results are shown in table 20. Many of the staff rated a large proportion of these potential advantages as very important. The percentage of clinicians who rated potential advantages as quite or very important ranged from 70.4% for work's role in reducing substance misuse to 97.8% for work increasing confidence and self-esteem. Financial gain from work was in the lower end of this range (79.2%) with the opportunity to meet people outside friends and family towards the upper end (96.7%). Although still commonly rated as important (84.7%), work promoting mental health was less strongly affirmed than most other potential advantages.

Ratings of the importance of the potential difficulties in working are described in Table 21. Again the majority of respondents rated all of the potential difficulties as quite important or very important. Taken together, the quite important plus very important responses ranged from 61.6% of staff rating people "not actively seeking work" as an impediment to working to 90.1% believing that stigma is problematic. The view that the stress of working might lead to a relapse was also particularly strongly affirmed with 89.1% of respondents reporting this as either quite or very important.

7.4.4 Staff attitudes and behaviour with patients

The majority of respondents (N=51) reported that the extent of the role they actually play in getting people into employment was "quite a lot" with only one person saying that this was not part of his/her job. Similarly over 90% of respondents said that they felt it was important for them to refer patients to employment services if they felt they were capable of working. When asked how much time staff would spend discussing employment with a patient 67% of respondents said "a substantial amount", with 24% saying "occasionally". Around 3% said that it was the main focus of several meetings.

Table 20: Ratings of the importance of the potential advantages of working

Type of advantage	Ratings of importance				
	Mean rating	Not at all (n) ¹ (%) ²	Slightly important (n) ¹ (%) ²	Quite important (n) ¹ (%) ²	Very important (n) ¹ (%) ²
Daytime structure	3.74	1 (1.1)	3 (3.3)	14 (15.4)	72 (79.1)
More money	3.14	2 (2.2)	16 (17.6)	39 (42.9)	33 (36.3)
Have a role in society	3.62	0 (0.0)	7 (7.7)	21 (23.1)	63 (69.2)
Autonomy and independence	3.58	1 (1.1)	8 (8.8)	19 (20.9)	62 (68.1)
Good for mental health	3.30	1 (1.1)	13 (14.3)	35 (38.5)	42 (46.2)
Meet people outside friends and family	3.60	0 (0.0)	3 (3.3)	30 (33.0)	58 (63.7)
Confidence and self esteem	3.77	0 (0.0)	2 (2.2)	17 (18.7)	72 (79.1)
Reducing the level of drug and alcohol use	3.03	6 (6.6)	20 (22.0)	29 (31.9)	35 (38.5)

¹Number of clinicians

² % of people who rated the advantage as not at all, slightly, quite or very important.

Table 21: Ratings of the importance of the potential impediments to people working

Type of difficulty	Ratings of importance				
	Mean rating	Not at all (n) ¹ (%) ²	Slightly important (n) ¹ (%) ²	Quite important (n) ¹ (%) ²	Very important (n) ¹ (%) ²
Benefits trap	3.51	0 (0.0)	11 (12.1)	23 (25.3)	57 (62.6)
Stress leads to relapse	3.30	1 (1.1)	9 (9.9)	43 (47.3)	38 (41.8)
Effects of medication	2.91	3 (3.3)	25 (27.5)	40 (44)	23 (25.3)
Low energy and volition	3.30	0 (0.0)	11 (12.1)	42 (46.2)	38 (41.8)
Stigma	3.42	0 (0.0)	9 (9.9)	35 (38.5)	47 (51.6)
Lack of specialist services to get people back to work	3.29	1 (1.1)	16 (17.6)	30 (33.0)	44 (48.4)
Positive symptoms	3.28	0 (0.0)	15 (16.5)	35 (38.5)	40 (44.0)
Lack of suitable jobs	3.22	3 (3.3)	17 (18.7)	28 (30.8)	43 (47.3)
Lack of encouragement and support	3.21	2 (2.2)	13 (14.3)	40 (44.0)	36 (39.6)
Over-reliance on state benefits	3.15	1 (1.1)	21 (23.1)	32 (35.2)	37 (40.7)
Not actively seeking it	2.76	6 (6.6)	29 (31.9)	37 (40.7)	19 (20.9)
People repeatedly not getting the jobs they apply for	2.78	9 (9.9)	24 (26.4)	35 (38.5)	22 (24.2)
Drug / alcohol misuse preventing people working	3.00	5 (5.5)	20 (22.0)	36 (39.6)	30 (33.0)

¹Number of clinicians

² % of people who rated the impediment as not at all, slightly, quite or very important.

Type of patient occupation (plumber vs office manager) did not appear to differentiate the advice staff would give a patient about convalescence before return to work, after leaving hospital with a psychotic episode. The majority of staff reported that this should be 2 months maximum.

7.4.5 Training

Figure 2 illustrates how confident the staff felt in assessing a person's capacity for employment and Figure 3 how much training staff had had in assessing this. Although the respondents were confident in assessing capacity for work, few had had any formal training in this area (16%). Out of the seventeen psychiatrists only four (23.5%) had had any training in assessing capacity for work despite potentially providing sick notes for service users. Of the total sample that had received some training, 58% said that this was either slightly or very effective. When asked how much training staff believed they should receive on the employment of people with psychotic disorders, 65% of people said that they wished to have a 1-day workshop.

Figure 2: The level of confidence expressed by clinicians in assessing whether someone with a psychotic disorder can work

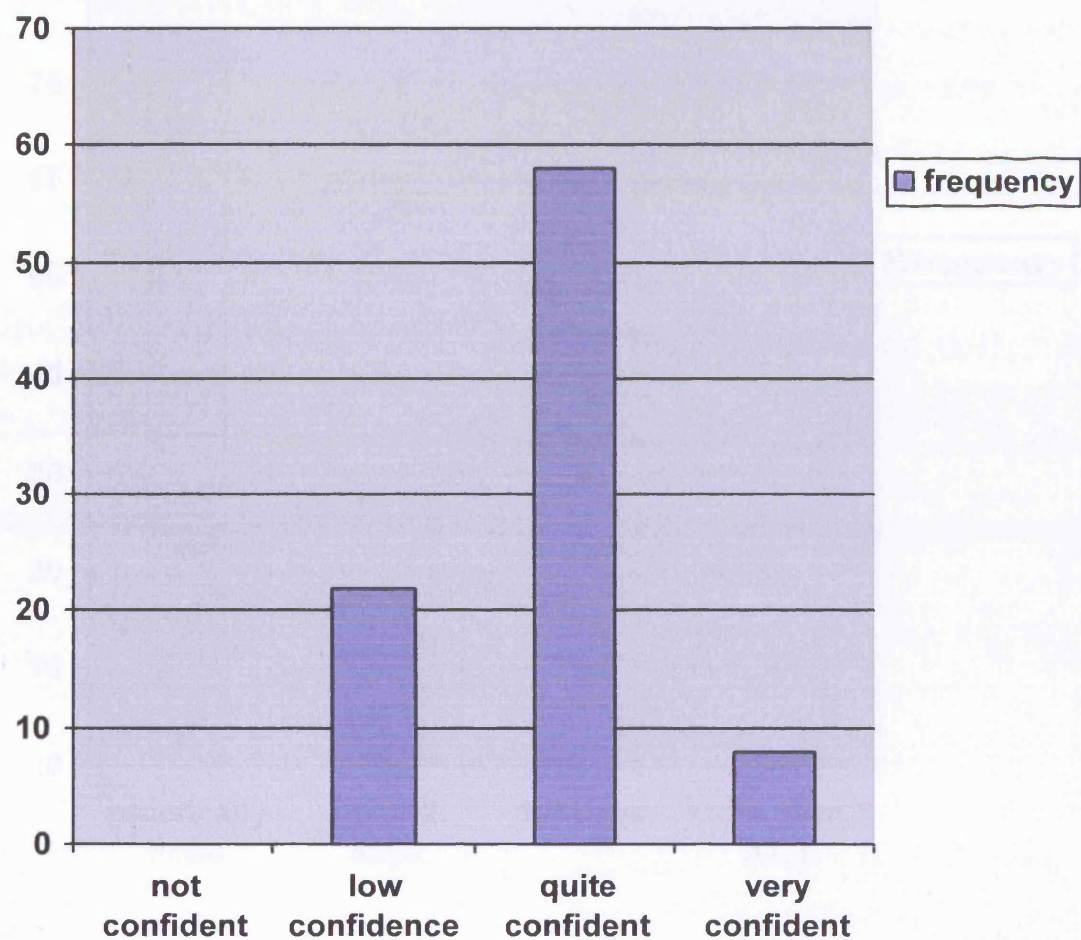
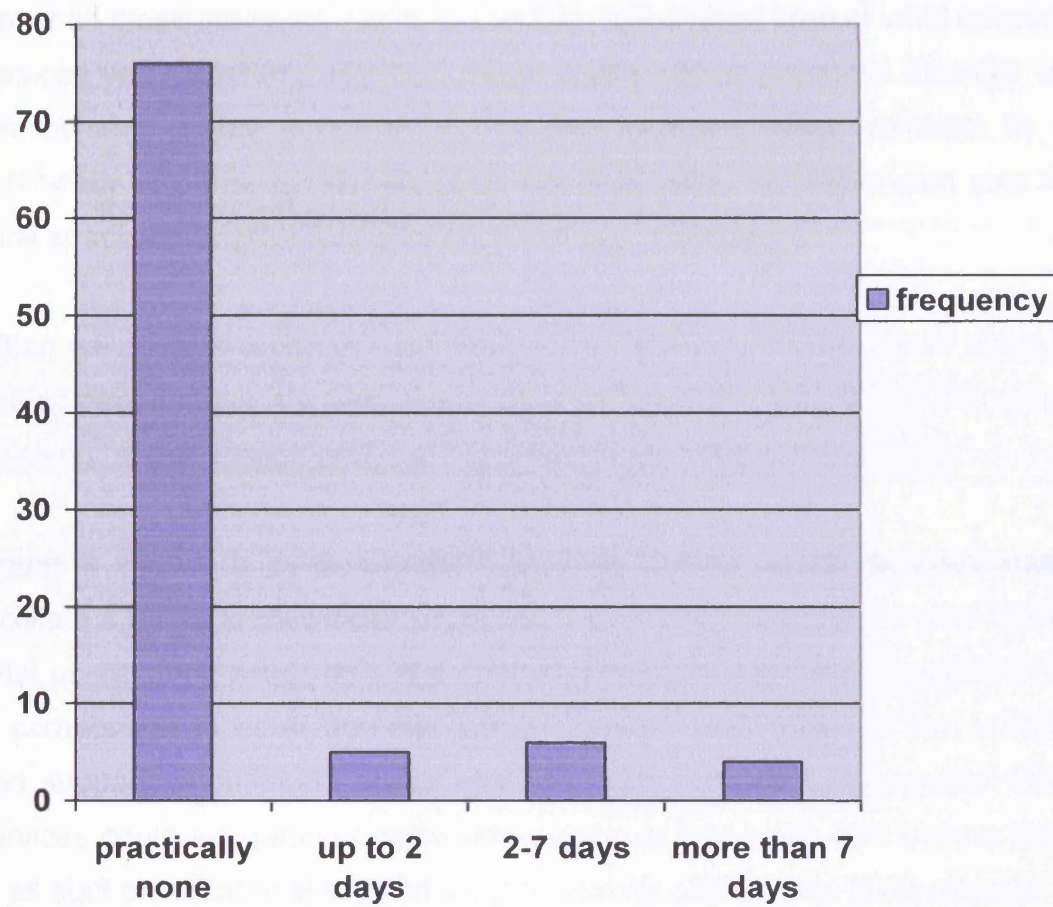


Figure 3: How much training have you had in assessing capacity to work in someone with a psychotic disorder



7.4.6 Opinions on services

Only half those surveyed reported that they had a good idea of what specialist services were available locally to help people with a psychotic disorder with employment issues and only a minority believed these services to be sufficiently effective at getting people into paid work. No respondent said that local specialist employment services were very effective.

When asked how much of a priority mental health services should place on getting people back into paid work approximately 60% of staff said this should be given “some priority” with 1 in 10 people suggesting a high priority.

Figure 4 shows in what way staff believed mental health services should facilitate a return to paid work for people with a psychotic disorder and figure 5 what priority they would give to a specialist employment mental health service in comparison to other potential service needs. Staff believed that a “place and support” vocational service was the most important way mental health services could aid getting people with psychosis into work, with training given to all staff on vocational support most frequently cited as the least effective. In comparison to other services that could potentially be invested in, a place and support vocational service was the highest priority for 30% of participants. This was exceeded only by “better inpatient services” which was given the highest priority by around 40% of respondents. Most people (86%) did not view mainstream services such as *Connexions* or the *Jobcentre* as useful for people with a psychotic illness.

7.4.7 Free Text

Only a few respondents completed this section at the end of the questionnaire primarily commenting further on the benefits trap. No further analysis is conducted of these comments.

Figure 4: How should mental health services facilitate a return to work

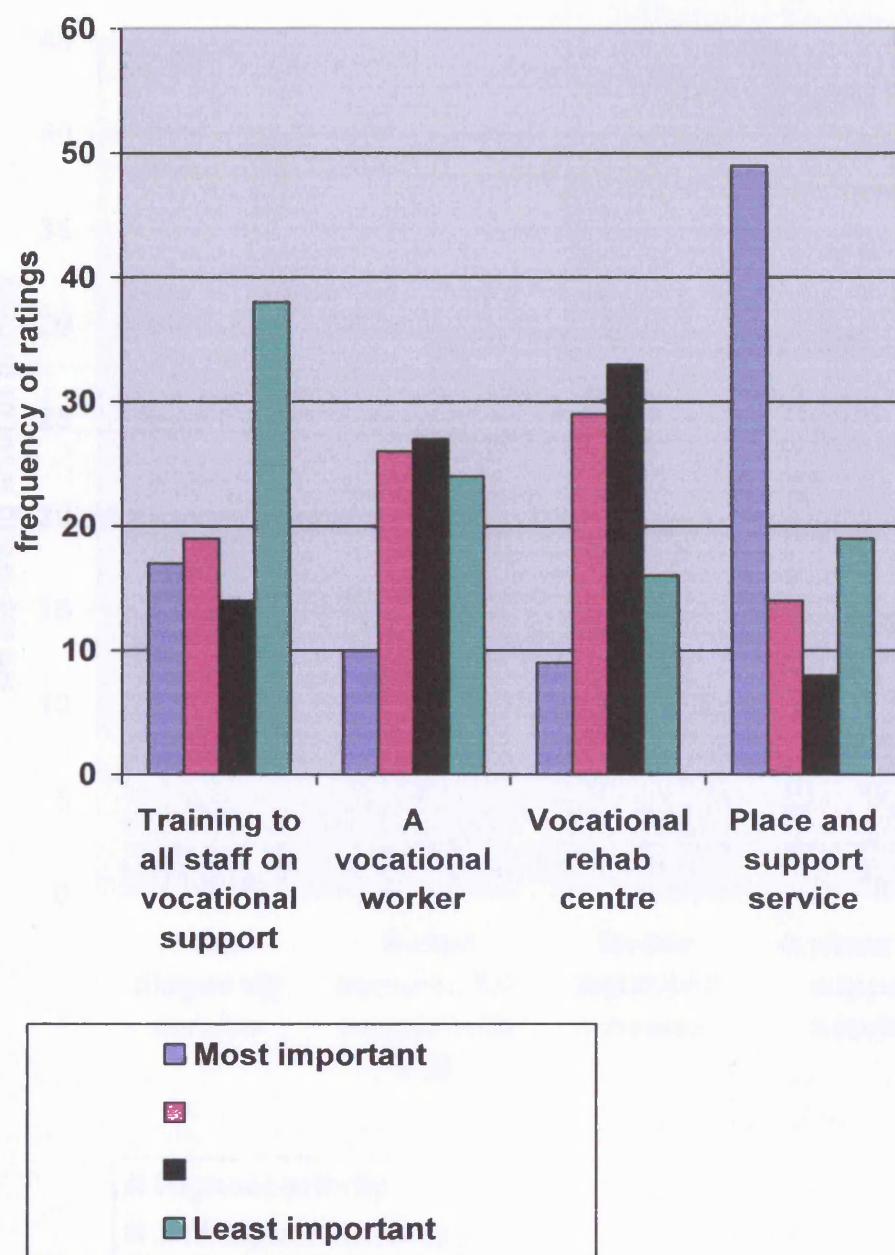
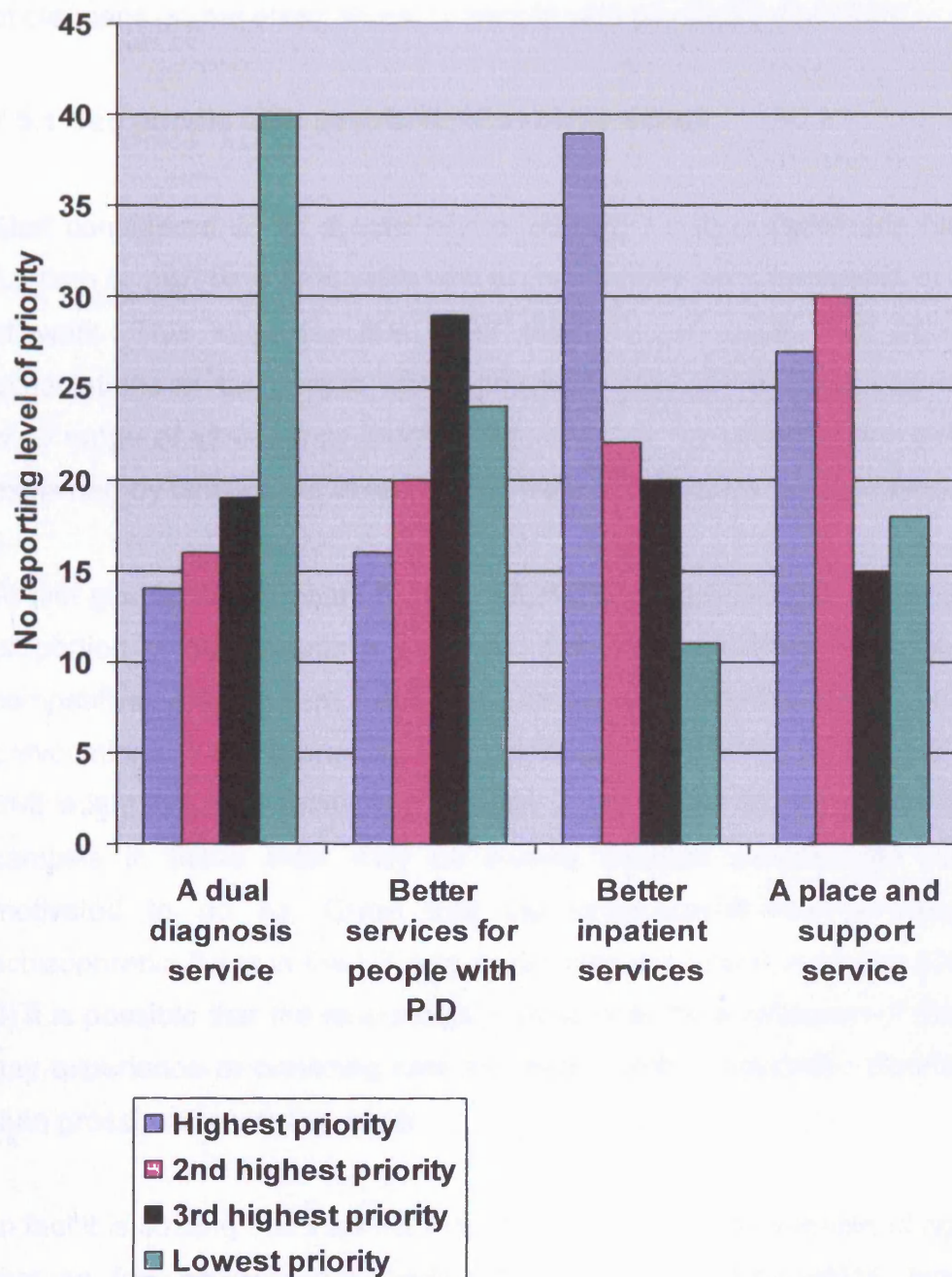


Figure 5: Priorities given to potential service developments assuming equivalent costs



P.D: Personality Disorder

7.5 Discussion

No substantial previous survey has investigated in a systematic way the views of clinicians on the employment of people with psychotic disorders.

7.5.1 Can people with psychotic disorders work?

Staff considered about a third of the patients on their caseloads capable of full-time or part-time paid work with approximately 40% incapable of any kind of work. This suggests that most staff do not have high occupational expectations of the people with a psychotic disorder on their caseload. The wide range of values may indicate that this is not a uniform view or could be explained by differences in teams that were approached to participate.

At first glance this appears to be a stigmatising view but we do not know the proportion of people with a psychotic disorder who actually are capable of competitive employment. Although randomized control trials of IPS vs prevocational training programs suggest that up to 50% - 60% of people with SMI might be able to work (Crowther et al 2001, Burns et al 2007), the samples in these trials may be biased towards people who are highly motivated to do so. Given that the employment rate in people with schizophrenia living in the UK and particularly in London is so low (Chapter 2, 3) it is possible that the respondent's views may be a reflection of their day to day experience of providing care for people with a psychotic disorder rather than grossly stigmatizing views.

In fact it is striking that staff believe so many people are capable of work given that so few on their caseloads are actually in employment. Indeed this disparity between the numbers they believe capable of work and the numbers that actually do so suggests that staff, although having low expectations are actually more positive than one might expect.

It was also interesting that staff reported approximately 30% of people with a psychotic disorder would be able to do voluntary work but fewer would be able

to do paid work although the tasks that a person carries out, or the skills required in both types of employment may be very similar in reality.

Respondents suggested that the majority of those who could manage paid work were capable of being a gardener, library assistant and a sales assistant. Most people working in such positions are required to possess a relatively low level of technical skill in the main. Also it is possible that being a gardener or library assistant are roles that may not usually be interpersonally demanding. Occupations that required more technical skills such as a computer programmer or police cadet were infrequently thought of as feasible for people with psychosis. This was the case despite the item in the questionnaire making it clear that appropriate training would be given. Thus it is possible that staff minimize the potential of patients or that the patients under their care tend to have substantial social and cognitive deficits precluding more demanding employment.

One exception to these trends was that staff did not believe people with psychosis would be capable of childminding even though young people or family members often do this without any formal child care qualifications. It is likely that staff held this view because of a perceived threat to children that someone with a psychotic disorder might hypothetically pose. Though the majority of women with a psychotic disorder have children, many of them have lost custody (Castle et al 2000).

7.5.2 Perceived advantages and barriers to people with a psychotic disorder working

A frequent response of the clinicians surveyed was that all the potential advantages of work listed in the questionnaire were very important, consistent with the views of people with a psychotic disorder themselves (Chapter 6). The view that employment would result in people with a psychotic disorder having greater financial resources was one of the least frequently endorsed attitudes. Such reservations by mental health professionals have been suggested previously (Perkins et al 1997). The potential advantages most

strongly endorsed by staff were related to the social and interpersonal aspects of employment, such as helping with confidence and self-esteem, provision of daytime structure and social contact outside friends and family. These are very similar to the latent functions of work as described by Jahoda (1981, 1982).

Concerns expressed by mental health professionals that working might actually damage the health of people with a psychotic disorder have been reported previously (Doherty et al 2004). The respondents in this survey also believed this to be the case, suggesting this even more frequently than the benefits trap as a barrier. Although no direct link has been proven between working per se and relapse of a psychotic illness, potential pathways are suggested by the wider literature. Discrimination in the workplace, which people with mental health problems report, has been associated with psychological distress and affective disorders (Wamala et al 2007). Also employment with lower job control (the ability to control working practices and time devoted to tasks, degree of autonomy), common in elementary occupations, has been linked with poorer health (Marmot et al 1997). On balance however, it is unlikely that the potential negative effects on mental health of working outweigh the well-substantiated damaging effects of unemployment on well-being.

It was interesting that out of all the potential barriers, the suggestion that patients often do not actively seek work was the least often endorsed. One potential explanation is that clinicians may believe that patients do actively look for work, at least for a time but that it is the other barriers that are more important in explaining the unemployment in people under their care. Also it may imply that some staff believe it is immaterial if people with psychosis look for work or not because other barriers will ultimately still stop them entering it.

7.5.3 Staff attitudes and behaviour with patients

The majority of staff reported that if they thought a patient was capable of work they believed it was their role to facilitate this, that they tended to discuss

employment and would refer them to employment services. This indicates staff believe that providing some type of vocational assistance is a core part of their role, contrary to previous reports in the literature (Bond et al 2001a, Grove and Membrey 2005). However the fact that only a tiny minority spend several sessions on enabling a return to work suggests staff view their role as initiating the process by which someone may find work, but not necessarily carrying this through, perhaps because of limits in expertise or time.

The respondents did not distinguish between a plumber and office manager in terms of how much time they would advise a person to rest for before a return to work after a psychotic episode. Given that most staff reported that their advice would be a period of two months before a return to work it is unlikely that clinicians are overly protective of patients in this respect. Neither does this suggest that staff believe people who have recovered from acute psychosis cannot then be capable of work.

There was, however, some disparity between these generally quite positive and enabling views and those expressed about the occupational abilities of people with a psychotic disorder on their caseloads. This may be explained by differences in contexts of the questions in the early and later parts of the questionnaire. Thus staff views appeared to be more positive when the subject matter concerned hypothetical patients with a psychotic disorder and more reserved and cautious when patients on their own caseloads were referred to.

7.5.4 Training

Although participants reported that they felt reasonably confident about assessing capacity for work, few had received any specific training in how to do this. Those who had had training found it helpful in their own interactions with patients. People felt they needed training in helping service users with a psychotic disorder to work, and most wanted at least a one-day workshop.

It is unclear how clinicians currently assess a person's capacity for work in normal day-to-day practice, given that they have little specific training in it. It is unlikely that this assessment occurs in a standardised way. Clinicians possibly form a general impression of the ability of a person to work using their knowledge of aspects of a person's functioning such as self care, ability to carry out activities of daily living, symptoms, medication compliance and side effects.

In contrast, a number of authors suggest that it is work expectation, motivation and work based skills such as the ability to do a specific task that should be used to assess if a person with a psychotic disorder will be able to get employment (Anthony and Jansen 1984, WHO 2000).

No recognized guidance on how to assess capacity for work is widely available, at least in the UK. Given the cost to the economy of people being off sick and claiming benefits is large, it is remarkable that clinicians with a very large role in deciding capacity for work have no real training in how to do so.

7.5.5 Opinions on services

Given that staff reported that they believe enabling employment to be an important part of their role, it was surprising that a significant number were not aware of the specialist employment services available locally. In any event they did not believe that such services were useful in getting people paid work, and this in itself may explain the lack of interest in them. There was also little faith in the ability of generic statutory services such as the job centre to help patients into paid work. The opinions of respondents on services was very similar to those reported by people with a psychotic disorder themselves (Chapter 6) and suggests that although staff recognize employment as important for patients, they have little in their armoury to do much about it.

The respondents gave a low priority to being trained themselves in vocational support, overwhelmingly suggesting that there should be a specialist employment service available to patients. This may have been to limit the

burden of additional interventions that they might have to carry out, or because of a lack of confidence in their skills in this area. Interestingly when asked to weigh the provision of specialist employment services against other potential priorities, better inpatient resources was rated as more important than a specialist IPS type employment service. People with a dual diagnosis have been identified as having poorer outcomes in terms of more severe psychotic symptoms, treatment compliance, housing stability and medical problems in comparison to people with SMI alone (Dixon 1999). Thus it was surprising that a specialist dual diagnosis service was given the lowest priority amongst the choices given to staff.

7.5.6 Limitations

There was a relatively low response rate of 66% although this is equivalent to a number of other surveys of CMHT members (Billings et al 2003, Priebe et al 2005). Information was not collected on the non-responders so it is unknown if they were different in terms of occupation, age or team, or if their opinions and attitudes would have been significantly different to study participants. A larger sample size would have allowed an analysis of whether demographic variables or professional background affected peoples beliefs.

Even though participants were assured that the questionnaire would be analysed in an anonymous manner the possibility exists that some of the answers were influenced by social desirability. A potential cause of this may have been that anonymity was not total, as respondents knew that the researchers were aware of the name number link coding of the questionnaires. Some of the respondents were professionally known to myself and the other individual (SB) who collected the data, and this may have influenced their responses.

Socially desirable answers may have been given especially for those questions that asked respondents to rate how important the advantages or potential impediments of working were. In answering these questions many staff rated most of the potential advantages listed as very important. This

limited the scope to differentiate which advantages staff believed to be most relevant. However, other results, such as the generally low estimates of the proportion of people with a psychotic disorder on caseloads who were capable of work, would suggest that if participants responded in a socially desirable way this was not widespread.

An issue in analysing any attitudinal data as in this chapter is that there is often a low correspondence between expressed attitudes and actual behaviour (Olson & Maiol 2003). Because of this, it is difficult to be confident that people's reports about their attitudes have a strong connection with what they do with patients in practice.

7.6 Summary

Overall clinicians have low expectations of the capabilities of people with psychosis to work. They believe people with psychosis are more likely to be capable of doing jobs that may involve a low level of technical skills. Few clinicians in the CMHTs that were sampled have had any training in assessing capacity to work but wanted to receive this. Clinicians report that helping people into work is a core part of their role and should be given some priority within mental health services. They did not however suggest that individual training in vocational support for CMHT staff was a desirable response to this need, endorsing the development of a specialist vocational service much more highly.

Chapter 8

Conclusions and Implications

8.1 Introduction

The main aims of this thesis as described in Chapter 1 are:

1. To describe and evaluate the current literature on the rates and correlates of employment status in people with schizophrenia and the barriers to working that these people face.
2. To explore the extent to which people with schizophrenia living in the U.K, France and Germany work.
3. To explore the factors associated with having a job, getting a job and losing a job in people with schizophrenia living in the U.K, France and Germany.
4. To investigate whether employment status influences psychotic and depressive symptom severity, subjective quality of life and general levels of functioning in people with schizophrenia living in the U.K, France and Germany.
5. To explore the views and experiences of working of people with severe mental illness.
6. To examine staff attitudes to people with psychosis working

In this final chapter I return specifically to these aims, summarise the previous literature and make concluding remarks on the main findings from the cluster of new analyses and studies described in this thesis. These findings are contextualised by making reference to previously published reports. I go on to consider the implications of my findings for clinical practice and policy and then argue for further research.

8.2 The literature to date on the rates and correlates of employment status in people with schizophrenia and the barriers to working that people face. (Aim 1)

There were surprisingly few epidemiological studies that reported an employment rate in people with schizophrenia and there were substantial methodological problems in comparing these as discussed in section 2.4.2. The UK employment rate in schizophrenia over the last 20 years ranges from 4 to 31%, with most samples reporting a rate between 10-20%. These figures are very low compared to the employment rate in the UK general population of 75-80%. The reported rates of employment from US samples also largely fall within this 10-20% band, especially from more recently published studies.

European studies excluding those based in the UK report very large variations in the employment rate between 1.5% and 43%. The only previous comparative international analysis of occupational levels from the EPSILON study group (Gaite et al 2002) suggests the possibility of genuine country level differences in the employment rate of people with schizophrenia in Europe. Though such comparisons of employment are rare they enable a more thorough understanding of the factors that influence employment because of the possibility of linking differences in labour market conditions, mental health and vocational services and the social circumstances of patients with rates of employment. The fact that studies based in Asian countries tend to report higher levels of employment, most likely because of social and economic influences, further supports the need for such comparative international research to explore these interactions further.

People with established schizophrenia on average have lower rates of employment than those experiencing their first episode of psychosis. It is conspicuous also, that in recent first episode samples many people are already unemployed, perhaps as a result of pre-morbid or prodromal difficulties during a period of undetected psychosis. Thus while some people experiencing the onset of a psychotic illness will need help sustaining a work

role that they already have, many will need help in initiating or recovering such roles.

It is possible that the rate of employment in people with established schizophrenia has fallen over the last 50 years in the UK, although the methodological caveats discussed in section 2.4.5.2 make this difficult to say with any degree of certainty. Although the reasons for this possible decline have not been clearly established, it is likely to be related to the interplay between social and economic factors, labour market conditions, the barriers that people face, provision of services and the individual choices people make depending on the incentives they have.

Although many factors have been reported to be associated with employment in schizophrenia, the most consistent and strong relationship appears to be with previous work history. Negative symptoms are likely to be important also, independent of any relationship to positive symptoms. Problems with memory and executive functioning appear to reduce the likelihood of a person with schizophrenia working. To some extent, cognitive problems may underlie the relationship between social integration, negative symptoms and work. The main demographic factor that appears to consistently predict better occupational functioning in people with schizophrenia as in the general population is a higher level of education. It is possible that younger age, male gender and not belonging to an ethnic minority are also significant. Whether any of these factors are specifically related to employment as opposed to overall good social outcome is unknown.

Several studies suggest that there is a correlation between employment status and other types of outcome. Although the evidence in the literature to date is not compelling the studies reviewed in section 2.4.7 suggest the possibility that employment may generalise to better global functioning and is correlated to clinical benefits such as reduction in symptoms or hospitalisations as well as better quality of life and self-esteem. Methodologically robust investigations of the causal direction of these associations are scarce.

There is a growing literature on the barriers to employment, which discusses potential issues such as stigma, concern over benefits, services and staff not being geared to supporting people in getting back to work, and discrimination from employers. Most studies of patient attitudes are quantitative surveys and it is noteworthy that smaller qualitative analyses have hinted at the doubts that people with schizophrenia have about employment. Although much is written and assumed about clinicians' attitudes to people with schizophrenia working, evidence to base this discourse on is limited.

8.3 The extent to which people with schizophrenia living in the UK, France and Germany are employed (Aim 2)

The analysis of the employment data of the EuroSC sample presented in Chapter 3 is one of very few international naturalistic comparative investigations of people with schizophrenia. It offers potential insights into the interaction between social, biological, service level and economic factors that may explain the nature of employment.

8.3.1 Employment rates in people with schizophrenia in the UK, France and Germany

As expected, in comparison to the general population people with schizophrenia in all three European countries had very low rates of employment. This was comparable to the findings of a number of large epidemiological and smaller surveys (Borga et al 1992, Middelboe et al 2001, Perkins & Rinaldi 2002, Haro et al 2003). Considering the results of the EuroSC sample and these other studies it appears that overall many European countries with widely differing types of government, economy, welfare policy and service provision have low rates of employment in the severely mentally ill compared to the general population. This suggests firstly that the explanation for these low rates is likely to be multi-factorial and secondly that it is unlikely to be easily remediable.

In the EuroSC sample Germany had the highest rate of employment (30%) using a broad definition of work and strikingly this was around three times the rate in the UK or France. Although the extent of differences were not as striking this pattern persisted whether people were working and supporting themselves entirely through their salary or whether they were working whilst claiming benefits. Despite overall rates being low in comparison to the general population, the EuroSC study as well as the results of others (Haro et al 2003, Lambert et al 2006) indicates that there may be significant country level variations in employment rates in people with schizophrenia across Europe.

8.3.2 Possible explanations for variations in employment rates found in the EuroSC sample

8.3.2.1 Vocational services

A potential explanation of why the German centres in the EuroSC study had the highest employment rates is that they also had the greatest number of vocational services and placements within these services compared to the UK and France. A significant amount of the vocational service provision in Germany appears to be in sheltered workshops and social firms. Despite the increasing evidence base that services emphasising pre-vocational training are less effective than supported employment, the German employment rates suggest that having a range of services may help to some extent.

8.3.2.2 Government policy

An additional potential determinant of the employment rates found in the 3 European centres in the EuroSC sample is government policies surrounding the employment of the disabled. These policies appear to be particularly extensive and developed in Germany. Both France and Germany but not the UK has a quota system requiring generally larger companies to have at least 6% of the workforce consisting of people with disabilities. In France this system was started in 1987 but has not been particularly effective (Mont 2004). Germany has developed a variant of the quota system such that

companies that do not wish to employ disabled workers pay a levy, which is then used to subsidize companies that are more willing, or the levy is used to fund other employment providers. Finally in Germany, unlike the UK and France, people with disabilities have a right to assistance to achieve a working life (OECD 2003) such that they are entitled to receive vocational rehabilitation services without having to demonstrate difficulty in securing work. Also a period of unemployment is not required before assistance can be sought and the degree of disability is immaterial.

8.3.2.3 The benefits trap

International variations in the level of the benefits trap faced by people with schizophrenia may be important in explaining differences in employment rates. Calculating comparable cross-national information on the level of disability benefits payable to people is however an immensely difficult task. Countries may have more than one disability benefit with different entitlements and these sometimes can be cumulated. Also differences in the rules on the rights of individuals to claim disability benefits can mean that in some countries these payments can only be obtained if a person has previously worked (OECD 2003).

Whilst it may be difficult to compare benefit levels between countries, there does not appear to be a clear relationship between the rate of disability benefit claims and employment rate in the disabled population. Thus at a macro-economic level higher rates of people receiving disability payments that might suggest a more generous level of entitlement do not seem to be strongly correlated to lower employment rates in the disabled population (OECD 2003). Outflow rates from disability pensions are also not higher in countries with a low level of benefits.

An alternative way to try to assess the extent of the benefits trap between countries is to ask vocational specialists. Assessments were made by IPS workers in the EQOLISE study of the likelihood of a worker having less in the way of finances if they took a job (Burns et al 2007). The risk was considered

high in London, UK and low in Ulm, Germany. This risk explained a significant amount of the heterogeneity in getting a job over time irrespective of the service received. If the risk of having less money if you work is indeed higher in London than in Ulm this would go some way to explaining why the rates of employment in the UK were so low and three times higher in Germany in the EuroSC sample.

Although the absolute benefit levels may not be important in explaining country level differences in the employment rates in the EuroSC study, rules governing benefits entitlements during the transition to work may be significant. Thus greater flexibility in Germany in comparison to the UK in the rules surrounding a return to work may help explain the differences in employment found. In Germany benefits are compatible with higher than pre-disability earnings at least for a time and the benefits can be reduced in stages (OECD 2003). Benefits also can be suspended for up to 6 months with an immediate resumption if work is unsuccessful for health reasons (OECD 2003). In the UK whilst benefits can be suspended for up to 1 year under “linking rules” introduced in 2002, benefits are only compatible with working up to 16 hours a week (OECD 2003). This may mean that the benefits trap is stronger in the UK than in Germany. Interestingly there is no provision at all in France to suspend benefits whilst work is tried.

8.3.2.4 Changes over time in the extent of part-time working

In Chapter 2, I suggest that there has been a possible decline in the rates of employment in people with severe mental illness in the UK over the last 50 years or so. This possible trend was reinforced by the finding in the EuroSC study of very low rates of working in the UK. A possible contributor to the very low rates of employment in the UK is the change in the patterns of work within the general population over the last 4 decades or so. In the UK in 1973 the degree of part-time employment as a proportion of total employment was 16% and this rose to 23 % by 2003 (Faggio & Nickell 2007). The rise in part-time work is likely to be a particular hindrance for people with schizophrenia given that it has been argued that the benefits trap is particularly severe for those

not working full time (Turton 2001). An equivalent figure for 2003 in Germany was 19% (Faggio & Nickell 2007) suggesting that more of the available work might be financially worthwhile there in comparison to the UK for people with schizophrenia.

This argument does not hold true however for the third country in the EuroSC sample. In France in 2003 the proportion of work that was part-time was only 13%, much lower than in the UK and Germany (Faggio & Nickell 2007) and yet the employment rate was still very low in the French centres. Thus it seems unlikely that in isolation the proportion of part-time / full-time work exerts a powerful effect on the rates of employment in people with schizophrenia. However the relationship between the availability of part time work in the general population and the employment rate in the severely mentally ill requires further disentangling. Despite the suggestion that disabled people entering part-time work suffer a bigger financial penalty than those in fulltime work, many people with schizophrenia are attracted to this working pattern at least at some point (Chapter 6, Meddings & Perkins 2002, Secker et al 2001).

8.3.3 Occupation and people with schizophrenia.

Few previous studies have documented the actual jobs that people with schizophrenia have or probed what underlies these patterns. The large sample size of the EuroSC makes such an examination feasible and meaningful. In order to understand the types of work people with schizophrenia do it is important to first examine how people work in the general population.

8.3.3.1. The nature of work in the general population

The nature of work has changed dramatically in Western societies over the last 50 years and increasingly this is the case within developing countries also. The change is both in terms of the occupations or primary lines of work that people do and more significantly in terms of the content of employment

such as the techniques, skills and technologies used (National Research Council (US) 1999).

The boundaries between many occupations have begun to disintegrate such that many work roles are much broader than was once the case and multiple skills are now often required to succeed in a job. The digitization of the work environment, which could potentially have resulted in a general reduction of the labour forces skills has in fact on balance probably increased requirements for technical skills in workers (Penn 1994).

The extent to which the quality of social interactions is critical to job performance is also rapidly increasing. The contact between employees within an organisation and customers is the basis of the expanding service industry and companies are increasingly competing on the quality of customer service (Albrecht & Bradford 1989, Reichheld 1996). Both qualitative case studies and quantitative research on the changing nature of blue-collar work have documented the importance of communication skills, problem solving, and coordination within and across teams (Adler 1993, MacDuffie 1996, Appelbaum and Berg, 1997).

Finally it has been argued that whilst professional and technical work has always involved rigorous intellectual skills, the degree of cognitive complexity of most work has and will continue to increase (National Research Council 1999).

8.3.3.2 The work that people with schizophrenia do

In the EuroSC cohort people with schizophrenia worked in all sections of the job market although entry into elementary occupations such as labouring was the commonest class of occupation. In the general population in the UK there is a much greater spread in occupational roles (ONS 2002) than that found in the EuroSC sample. Elementary occupations by their nature are characterised as being low paid and low skilled and are often transitory, offering little

protection from dismissal. It is also likely that the tasks involved in this type of role lack significant cognitive complexity.

People with schizophrenia may have a propensity for these types of occupations for a number of reasons. The cognitive deficits that they have (Green et al 2000) may mean that in a modern western labour market they are increasingly excluded from higher paid occupational roles given that these usually also tend to involve greater cognitive complexity. Social skills deficits and other negative symptoms may also have an influence.

Although the evidence is not beyond dispute previous authors have suggested that the severely mentally ill have a preference for employment which involves low levels of interpersonal interaction (Bacani-Oropilla et al 1991, Muntaner et al 1993) and that interpersonal difficulties are important in explaining job loss (Wong et al 2001). Elementary occupations may typically involve low levels of contact with others also and this may in some way explain the higher proportion of people in the EuroSC sample working in such roles.

It was interesting that in the EuroSC sample, the skilled trades were the second most common type of occupation that people with schizophrenia were doing. Typical examples of such trades are bricklayers, sheet metal workers, motor mechanics and electricians. Although better paid than the elementary occupations they may still involve low levels of person to person contact or need for communication skills.

As the nature of work has become more technical and communication based the cognitive and negative symptoms that people with schizophrenia may have, may mean they are less equipped for the bulk of available jobs than was once the case. This change in the availability of different types of work may explain the occupational patterns found in the EuroSC sample.

Although it is likely that the nature of work and the illness related problems that people with schizophrenia suffer have an effect on the types of occupational roles fulfilled, there may be other reasons for this picture also.

For example discrimination by employers may force people with schizophrenia into lower paid and unskilled jobs. How far factors such as the choice of individuals or the opportunity for untaxed work, which people may feel is necessary to make work pay affects the patterns of occupation found is unknown.

8.4 The factors associated with having a job, getting a job and losing a job in people with schizophrenia living in the UK, France and Germany (Aim 3)

The EuroSC study enabled an examination of the associations with employment of a wide range of factors in a naturalistic follow-up. Most previous studies exploring the predictors of work status have either had small sample sizes, are cross sectional in nature or have been evaluations of vocational interventions.

8.4.1 Cross sectional analysis

The results of the baseline analysis of the EuroSC data corroborate a number of previous common findings from cross sectional studies suggesting general psychopathology symptoms and education influence employment (Rosenheck et al 2006, Rogers et al 1991). Unlike many previous reports suggesting an association between severity of positive and negative symptoms and work (Schulderberg et al 1999, Priebe et al 1998) no such robust link was found in the cross sectional analysis of the EuroSC. Any potential association with symptoms may have been confounded by the association of higher odds of working with a single episode of illness and lower odds of working with a continuous illness course. Though it is relatively uncommon for research to examine the effects of illness course on work status, the results of this analysis are consistent with the findings of Rosen and Garety (2006) describing better employment rates in people who have experienced a single episode of illness.

8.4.2 Analysis of the prospective data

No previous large naturalistic study has examined the predictors of getting a job and losing a job prospectively within the same sample. In the EuroSC dataset there was some overlap in the factors that explained being in employment at baseline and those that explained obtaining and losing a job prospectively, but also areas of divergence. Area of residence influenced all three dependent variables, although the direction of action differed depending on the centre and which employment variable was being investigated. Area of residence is likely to encompass many potentially important elements such as urbanicity, nature of the local economy and social welfare rules. In short it is likely to represent the wider social and occupational environment.

Independent of the effect of area of residence, higher local population employment rate impacted on employment status prospectively, increasing the odds of getting work. This was similar to number of previous reports (Warner 2004, Cook et al 2006). Using correlational analysis Kilian and Becker (2007) have also reported a relatively strong positive link between general population employment rate and the rate in people with schizophrenia for many developed countries. Interestingly in the EuroSC sample, local employment rate did not influence the chances of prospectively losing a job suggesting that once in work, a person's functioning and success in it may be more important than general labour market factors.

In order to understand which clinical and social factors are important in predicting getting a job, it is useful to return to studies within the current literature to compare the results of the findings from Chapter 3 and 4. A previous large scale naturalistic study has reported that more years of education and male gender increased the odds of employment whereas more severe positive and negative symptoms, depression and African American ethnicity all predicted worse employment outcomes (Salkever et al 2007). Also poor self rated functioning, negative psychotic symptoms, co-morbid substance misuse and recent hospitalization was reported to damage employment prospects over time in a 24-month multi-site longitudinal

evaluation of supported employment (Razzano et al 2005). Both of these studies control for work history, a known robust predictor of future work in their analyses.

Prospective analysis of the EuroSC dataset replicates many of these findings although it was not possible to control for previous work history. Because of a lack of consistency in data collection of ethnicity across sites it was unfortunately also not feasible to investigate fully the effects of ethnic background on employment prospects. Unadjusted analyses at least in the UK and France did not suggest an association though small numbers of ethnic minority participants may have meant there was limited power to detect a difference.

Older age of illness onset and longer length of illness were also significant in reducing the odds of obtaining employment in the prospective dataset with the former also being significant at baseline. The size of the effects are however fairly small. As suggested in section 4.5.2.1, older age of illness onset (defined as presentation to services) may reduce the odds of working because of its association with longer duration of untreated psychosis. Longer length of illness is likely to be important because of the cumulative social disability that people with schizophrenia may experience over time.

Only a limited number of studies have previously examined the association of substance misuse on employment and surprisingly some have found no effect (Goldberg et al 2001, Bond et al 2001b). Both alcohol misuse and drug misuse were important in the EuroSC sample and damaged occupational functioning, replicating the findings of Razzano et al (2005).

In the series of regression models testing the associations between the PANSS symptom sub-scores and employment, general psychopathology and positive and negative psychotic symptoms explained distinct aspects of the getting a job, being in job, losing a job cycle. Thus whilst more severe general psychopathology and negative psychotic symptoms reduced the likelihood of being in employment and getting a job respectively, more severe positive

psychotic symptoms at baseline increased the odds of losing employment at follow-up. The size of the effect for all symptoms was however small.

Severe negative symptoms probably prevent a person from looking for work or affect the motivation required to persist in doing so. Thus if negative symptoms have not inhibited a person from getting a job through the application and interview process, they may not be severe enough to significantly influence a person's functioning at work. In such circumstances, unless there is a worsening in mental state, negative symptoms may not then influence whether a person will lose that job. General psychopathology symptoms encompass a variety of aspects of interpersonal functioning, cognitive skills and anxiety levels, all of which can probably affect the ability to do many forms of work.

The effect of positive symptoms at baseline on the prospects of losing a job over time are intriguing given that previous reviews (McGurk and Mueser 2004, section 2.4.6.10) suggest that this association is not at all robust. It may be that coping day to day with positive symptoms at work can over the longer term have a cumulative damaging effect.

The findings from this thesis add significantly to the very limited current literature base reporting ethnic minority status (Fabian 1992), exacerbation of functional psychosis (Watzke et al 2006) and low educational level (Salkever et al 2003) as all being associated with job loss. To some extent it was surprising that any static baseline factors predicted the odds of a person losing a job over the two year follow-up period in the EuroSC study. Intuitively one would think that immediate problems between the employee and employer would be far more important than baseline factors once someone was in a job. However alcohol misuse and more severe positive psychotic symptoms at baseline increased the odds of job loss although it is unknown whether these problems persisted or worsened over time. Possessing some vocational training protected against losing employment. Having some vocational training suggests a particular skill set and is likely to be a protective factor because the pool of other people with these skills may be limited. In

essence the employee with vocational training may be more valuable than one without irrespective of whether they have a mental illness and this might lead the employer to be accommodating.

8.4.3 Summary of socio-demographic and clinical factors that predict employment status

In summary, considering the current available literature and the results of the series of analyses based on the EuroSC sample, a number of reasonably robust conclusions can be drawn about the socio-demographic and clinical factors that predict employment status. A higher general population employment rate is linked to better employment prospects for the severely mentally ill. A more significant work history and a higher level of education also boost the chances of working. More severe illness course, alcohol and drug misuse and negative psychotic symptoms all damage the odds of employment. It is possible although by no means certain that PANSS general psychopathology and positive symptoms also reduce the odds of working. The findings that vocational training, age of illness onset and length of illness are important influences on occupational functioning require replication because these variables are not frequently examined in previous studies.

8.5 The influence of employment on other outcomes (Aim 4)

The preliminary results in this thesis suggest that employment status may have an effect on other social and clinical outcomes, although a full range of possible explanatory variables was not controlled for in the analyses. Sustained employment was associated with higher general levels of functioning, general life satisfaction (an aspect of quality of life), lower general psychopathology and positive psychotic symptom scores and lower odds of depression at follow-up. Getting a job was also associated with higher general functioning and lower positive and general psychopathology symptoms scores. It is not possible to be sure of the direction of causality from this analysis.

It is important to note that working was not associated with a deterioration of symptoms or functioning, a common belief amongst staff (Doherty et al 2004) and patients (Garske & Stewart 1999). However job loss was linked to more severe positive symptoms at baseline and therefore it is possible that the group who lost their jobs did so because of an exacerbation of symptoms.

Despite the caveats, the fact that employment did have positive effects in other domains is encouraging, and suggests that advocating people with schizophrenia return to work is supported to some extent by evidence that this may benefit their health and well-being.

8.6. An exploration of the views and experiences of working amongst people with severe mental illness (Aim 5)

In comparison to many previous questionnaire studies, the use of a qualitative methodology allowed for a more in-depth understanding of why so few people with SMI work although most express a desire to do so.

8.6.1 The theory of planned behaviour

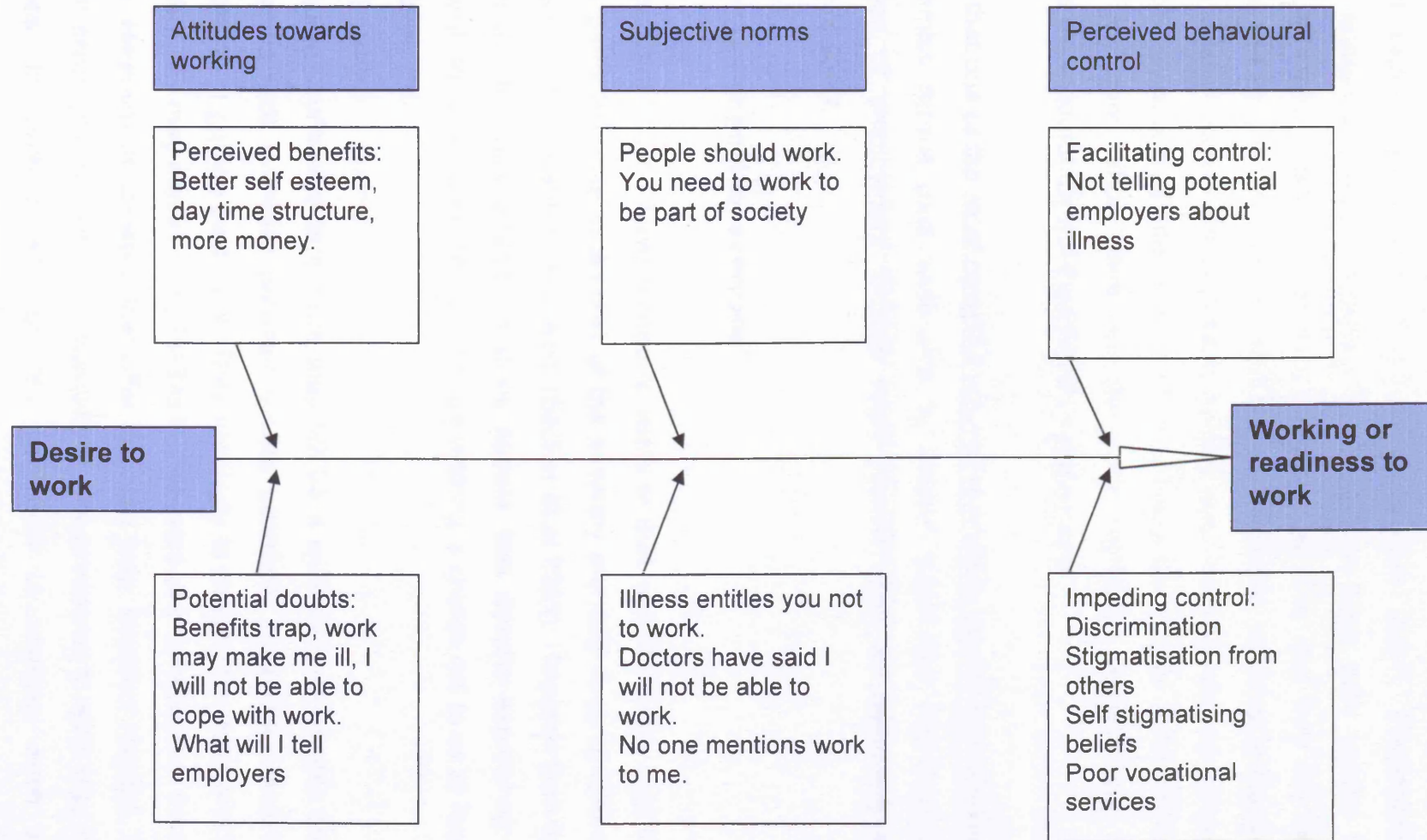
A means to explore the complexities of this area is to frame people's opinions and attitudes within the scheme suggested by the theory of planned behaviour (Ajzen 1985). This psychological theory is a way to examine the extent to which attitudes and intentions predict actual or readiness to complete a behaviour. It suggests that three essential components can be used to mathematically predict how likely it is a person will carry out an action. These components are: attitudes towards the behaviour; subjective norms (perception of social pressures towards the behaviour); and perceived behavioural control (how easy it would be to perform the behaviour and beliefs about what factors may impede or facilitate the behaviour). In a meta-analysis of 185 studies Armitage & Connor (2001) report that this theory is effective at predicting a significant amount of the variance associated with a broad range of behaviour and behavioural intentions, such as response to advertising or deciding to stop smoking.

8.6.2 Using the theory of planned behaviour to examine choices that people make regarding work

This theory can be used to examine why the desire to work that people with schizophrenia express is often not translated into action. Given the qualitative nature of the investigation completed for this thesis mathematical modelling is not possible. Instead Figure 6 frames this potential explanatory model in diagrammatic form. The content of each of the boxes is not exhaustive but gives examples of themes that were evident in the thematic analysis described in Chapter 6.

In terms of attitudes to work as in many other studies people reported numerous potential advantages. These however seemed to be balanced by the substantial doubts about the transition into working life including concerns that they would be financially worse off, that they were not well enough to work and that working might damage their mental state. With regards to subjective norms from society it was clear that respondents felt under considerable pressure to work, although they also implied that people who were unwell were entitled not to work. This latter idea was very similar to the descriptions of the rights of the sick person suggested by Parsons (1951). In support of this idea was the report that doctors had suggested that they should not be working or would not be capable of doing so.

Figure 6: Using the theory of planned behaviour to explain readiness to work or actual work



The component of the theory of planned behaviour that is most predictive is perceived behavioural control (Armitage & Connor 2001). Participants reported numerous factors impeding the extent of their own control in returning to work; in other words they believed that they had very low self efficacy in this respect. In contrast respondents described little that enhanced their own level of control with regards to getting work, the only obvious attitude being that they would choose not to tell employers about their illness when applying for work. Thus there are far more significant impediments to perceived behavioural control than factors supporting it.

It seems that one of the most powerful ways of exercising control over working is to dismiss formal paid work and to simply obtain the non-financial advantages of employment through other means such as becoming an advocate or carer.

8.6.3 Is work the goal for everyone?

Throughout this thesis I have tended to assume that working is the goal for everyone partly because in surveys of the severely mentally ill up to 90% of people say that they want to be in work (Secker et al 2001). However from the results of the thematic analysis it does appear that despite expressing a general wish to work some people may be making a choice not to or at least not to actively try.

In developing countries where there may not be a welfare state, people with schizophrenia face a choice between severe economic deprivation and its consequences or getting paid work. They are likely to choose the latter and to some extent this may explain the possible higher rates of employment in these countries. However in societies that offer financial help, however meagre, to those with schizophrenia who are unemployed, the pressures to work may be much less. In such a situation the obstacles to working, such as discrimination, loss of benefits, and low perceived behavioural control may become much more powerful in the decision making process, as may the nature of the work available. This may mean that people choose not to work

because of the barriers that they face and because they may have other sources of satisfaction in life.

Choice is usually considered a good thing but in the case of employment in people with schizophrenia, exercising this choice may mean that working is not a goal for some who could feasibly work given the right opportunities. Whether people should be allowed to exercise this choice given the financial and social cost to others is essentially a moral question. It does appear however that currently both sides of the political divide in the UK increasingly believe that if people are capable of working then they should do so.

8.7 Staff attitudes to people with psychosis working (Aim 6)

Although the current literature suggests that clinicians' attitudes are a significant barrier to people with SMI working (Vogel et al 1989, Goldberg et al 2005, Bond 2001, Grove and Membrey 2005) this view has largely been derived from expert opinion and a small number of studies. There has been no previous UK substantial survey on staff attitudes to people with psychosis working. In the study completed for this thesis staff from 9 community mental health teams reported that more people with SMI on their caseloads were capable of paid work than were currently in employment but that 2 in 5 were incapable of any paid work.

Occupations that were most frequently cited as being suitable for people with SMI were those that tend to require a low level of skills or that are generally interpersonally undemanding. The views of clinicians on what types of jobs people with psychosis would be able to do were similar to the actual occupations of people with schizophrenia in the EuroSC sample.

Staff were frequently concerned that working might damage the mental health of patients as suggested in previous reports (Goldberg et al 2005) and as reported by patients themselves (Chapter 6). Although a theoretical possibility (Marmot et al 1997) this is a view that is contrary to the limited evidence available (Bond et al 2001a, Chapter 5). Participants reported that a core part

of their role was to help people with SMI negotiate a return to work, although the amount of time that they dedicated to this was limited. Despite expressing some confidence in their ability to assess a service users capacity for work most clinicians had received very little training in how to do this. The majority felt they could benefit from some training.

Few people were confident in their knowledge of what specialist vocational services were available locally and they did not believe that those to which patients had access were effective in getting people back into paid employment. Clinicians suggested that ideally a specialist place and support service should be provided for patients, but they gave improving inpatient services a higher priority overall.

In general the survey of CMHT clinicians does not suggest that staff have entrenched, stigmatising and unhelpful attitudes to people with SMI working although it is conceivable that some people hold such beliefs. Some views such as the belief that people with psychosis would be better able to work in jobs involving low levels of technical skills could be labelled as discriminatory. They may also simply be reflections of clinicians' experiences of supporting people who have a severe mental illness. Attitudes were actually more positive than one might expect but it appears that clinicians working in Camden and Islington do not feel they have much in the way of resources to help people with SMI into work despite believing this to be important.

8.8 Implications

Thus a variety of conclusions, some clear and others as yet tentative can be drawn from the cluster of studies presented in this thesis. These conclusions have a range of implications for clinical practice, research and policy, which will now be discussed in turn.

8.8.1 Clinical implications

Although employment prospects are impaired in people with a continuous course of illness there was no substantial relationship between positive symptoms and having a job at baseline or getting a job in the follow-up analysis. This suggests that the presence of positive psychotic symptoms does not automatically mean that someone will not be able to work.

Symptoms coded by the general psychopathology PANSS sub-score such as depression, anxiety, social avoidance, impulse control problems and cognitive deficiencies appear to have the potential to damage employment prospects. Which are important in practice cannot be identified from the findings of this study. However, other work (Resnick et al 2004, Sim et al 2004) suggests that depression and anxiety are commonly comorbid in schizophrenia and are often missed or go untreated but which damage employment and other aspects of recovery. Thus these findings strengthen the case for the assessment and treatment of comorbid problems in schizophrenia. With regards to neuropsychological problems cognitive remediation therapy is effective (Wykes et al 2007) but is not widely available and it is not clear whether gains made in cognition may then generalise to other outcomes such as work.

Comorbid alcohol and drug misuse also damage the ability of people with schizophrenia to work. Treating such dual diagnosis patients is difficult (Cleary et al 1999) and it remains to be seen if effective interventions can be developed that not only reduce the level of substance misuse but also as a results effect improvements in aspects of social functioning.

Further, as in the studies reporting IPS outcomes, there is no evidence from the analyses in this thesis that working itself leads to a worsening of psychotic symptoms or deterioration in the mental state of people with schizophrenia. Although this needs further investigation, currently there does not appear to be a reason why clinicians should be overly cautious or restrictive about

advocating or supporting people to work on the grounds that it might damage health.

Surprisingly number of years of general education was not significantly associated with work status in any of the regression analyses. Thus it appears that disrupted education in childhood should not necessarily be thought of as hindering future employment prospects as long as qualifications are eventually obtained. As in the general population (Walker & Zhu 2003) higher education was an important determinant of work status in people with schizophrenia. The possession of a diploma or degree and vocational training increased the odds of having a job and protected against losing a job respectively. This supports the emphasis in current UK mental health policy on encouraging people to re-integrate into education early after a first episode.

Self stigmatisation, low self confidence and self efficacy appear to be important impediments to preventing people with schizophrenia working and these patterns of thinking are similar to those found in the long term unemployed in the general population (Harris et al 2002). Group based CBT type interventions have been shown to be effective in improving self efficacy and subsequent job seeking behaviour in the general population (Proudfoot et al 1997, Creed et al 1999) though this has not been consistently replicated (Harris et al 2002). Though speculation it is possible that individual clinicians providing simple educational or cognitive input along these lines might help improve the confidence of people with schizophrenia.

8.8.2 Service implications

There appeared to be some association between greater vocational service provision and higher employment rates in Germany. The types of vocational services available in the German centres were sheltered workshops and social firms and it appears that this is a well disseminated model with Germany having the largest number of social firms outside Italy (Warner & Mandiberg 2006). There is a significant demand from both service users and staff for increasing the priority given to specialist employment service

provision. Tackling the social exclusion faced by the severely mentally ill is central to a number of UK policy documents (Social Exclusion Unit 2003, Department of Health 1999), but changing the employment patterns in people with schizophrenia is likely to require substantial funding for vocational service development if the situation is to be ameliorated.

8.8.2.1 Potential types of vocational service provision

There is now mounting evidence from countries with differing welfare systems (Lehman et al 2002, Latimer et al 2006, Burns et al 2007) that the individual placement and support model of vocational assistance is more efficacious than prevocational training in helping people with SMI into work. This strong evidence base should underpin a call for more widespread implementation of this type of service.

There are however, a substantial number of people who enter supported employment programmes for whom the intervention is not effective. It may also be the case that many more people who are approached about the opportunity to receive this intervention refuse than accept. It would seem unlikely that every person with SMI will be able to achieve open market employment in any case or indeed wants this. Thus in the UK there is considerable scope for developing a much more coordinated and widespread range of employment services for the severely mentally ill that encompass IPS as one component.

One potential policy might be to focus on the development of many more social enterprise firms as in Sweden (Ministry of Finance, Ministry of Industry, Employment and Communication 2004). Social firms are market led businesses, which are formed and run for the employment of people with a wide range of disabilities that are disadvantaged in the labour market. People are normally paid the market rate for the job that they do. Although there are a number of criteria that companies might use to define themselves with as social firms (Social Firms UK) the principles centre on the fact that the

organisation needs to be a viable business, which emphasises employment rights and empowerment for workers.

An obvious advantage of social firms for people with schizophrenia would be that they would not have to combat the discrimination in the work place that they perceive. In the language of the theory of planned behaviour there would be greater perceived behavioural control and this in itself may push the balance for many people towards work. The success or otherwise of social firms in offering employment to the severely mentally ill is an under-researched area.

Although the supported employment movement has repeatedly demonstrated its advantages over pre-vocational training services such as sheltered workshops in getting people into open market work it is possible that such workshops offer some function and benefit to people none the less. These functions may be social contact, daytime structure and some form of occupational therapy. However the position of sheltered workshops in an environment of increasing evidence for IPS as the best way to get people into work is unclear.

8.8.2.2 Provision of information about benefits payments and work

The lack of knowledge expressed by service users and clinicians about the financial consequences of working compared to remaining unemployed suggests that there is also a pressing need for information about this to be much more accessible. This might be usefully coupled with mental health services or could be part of some more mainstream provision for the disabled. It would also be useful for mental health professionals to have some sort of basic training on benefit payments and work.

8.8.2.3 Training

Clinicians view the employment of people with psychosis as important and an area in which there is scope for much greater emphasis and priority. They also

identify their lack of any training about how to assess capacity for work. The possible consequences of this lack of knowledge are that the subject of employment may simply not be discussed with service users as they have suggested (section 6.4.5). Also clinicians might label service users as incapable of working or only capable of doing certain jobs when this is not the case. The views of clinicians may subsequently have an effect on a person's benefit entitlement.

The lack of training for clinicians is relatively easily remediable and most staff surveyed (Chapter 7) asked for a 1-day training course. The current evidence base on how to assess capacity for work however is far from complete and our knowledge is still developing.

8.8.3 Implications for policy development

Employment is inevitably a political subject given that it normally represents economic activity and thus is one measure of the success of a government. As the employment rate in the general population in the UK has slowly risen in the last decade (Department for Work and Pensions 2007), the group classified as the long term unemployed have become the focus of greater political attention. A significant proportion of this group are people with schizophrenia. Thus there are several potential policy implications of the main findings of this thesis.

8.8.3.1 Government policy

One of the main barriers to working for people with schizophrenia in the UK, suggested by both patients and staff, is the fact that a transition to working life from one on welfare benefits may not be financially worthwhile. There is a natural tension between the amount of provision of state benefits to sustain people who cannot work and the extent to which the level of provision makes the move to employment financially unrewarding. A considerable amount has been written in the literature and in governmental policy documents about tackling this fiscal choice, although a clear answer has not emerged, partly

because the welfare and economic systems and political priorities of countries are different and frequently changing (Mont 2004).

In the European Employment Strategy 2003 (European Commission 2003) “making work pay” is one of the key guidelines aimed at achieving better employment rates overall. Many such policy initiatives tend to be targeted primarily at the unemployed who are not receiving disability payment but are equally valid for people with SMI. Suggestions for modifying the benefits trap include tax cuts for low income earners and altering the earned wage thresholds at which welfare benefits are withdrawn. Another potential area for intervention may be the ease with which people may reclaim benefits should employment break down. Also as proposed by the UK government in the Welfare Reform Act 2007, it is possible that the potential for benefits to be reduced if a claimant does not engage in work assessments or is considered not to be actively seeking work may act as a lever motivating people to get work.

8.8.3.2 Policies aimed at employers

People with schizophrenia report discrimination from employers as a significant barrier to them getting a job and given that stigmatisation of the mentally ill in the general population is high (Crisp et al 2000) this seems likely. Faced with an applicant with a psychiatric illness, employers might have a number of dilemmas. There may be a perception that the severely mentally ill may take a large amount of sick leave, costing the company more money than would otherwise be the case because of the need for back fill. Also employers may believe people with schizophrenia or people who are psychotic are dangerous or unapproachable (Crisp et al 2000). Apart from the potential concerns about risks that might be posed by hiring a person with schizophrenia, certain types of businesses may simply require people with a high level of interpersonal skills which some severely mentally ill people may have deficits in. Finally some employers may feel that a number of jobs such as teaching children or being in the police force are incompatible with an illness such as schizophrenia. Such a decision may not be based on potential

skills sets that people do or do not have but on the fear of potential negative media coverage or litigation should an adverse event occur.

As a first step, a potential solution may lie in directly educating larger employers about mental health problems, persuading them to accept the possibility of people becoming unwell, educating them about the risks involved and in making support available to aid in resolving issues that may arise.

Another strategy targeting employers that is not currently used in the UK but is common in many other countries (section 1.6.2) is a quota system. Although it might be unpopular with the business community, in such a system larger companies are required to employ a certain percentage of their workforce with disabilities.

8.9 Areas for further research

Whilst the analyses and new studies presented in this thesis add to the previous literature on the rates and correlates of working, the knowledge base remains relatively small. There are a number of areas that justify further significant study.

8.9.1 Further exploration of international employment patterns

The degree to which the employment rate of people with schizophrenia varies internationally and the factors that may underlie such variations warrant further investigation. Very few comparative analyses exist, yet they offer a vehicle by which we may better understand how the social and mental health service environment affects the employment rate of the severely mentally ill. Ideally a study that had many different centres with a wide range of characteristics is needed. This would then enable a fuller exploration of the relationships between area level variables such as services, welfare systems, and general population employment rates with the employment rates in people with schizophrenia.

Also further understanding the apparently higher rates of employment in developing countries may help social policy planners in the UK and other western countries.

8.9.2 Investigation of the extent to which people with schizophrenia work in the unofficial job market

Although the employment rate of people with schizophrenia living in the UK and especially in cities appears to be very low, our knowledge of the numbers working in the unofficial or “black market”, perhaps unsurprisingly is minimal. The black economy, which is normally described as economic activity not declared to the state in order to avoid tax and other obligations, has been estimated at 10.6 % of GDP in the UK (Economic and Social Research Council 2007). It is possible that a significant number of people with SMI work in this way.

Though it is feasible that some of the declared jobs in the EuroSC and other analyses are not legal it may be that most people working in the unofficial labour market do not inform researchers that they are working. Thus the evidence base on people who are employed may actually be rather biased currently. Anonymised surveys may be a method to gather data on the size of participation in this part of the economy. It is also possible that people with schizophrenia might be more inclined to divulge this type of information if it was service users themselves who were conducting the research. Service users might also be better placed to elicit honest accounts of people’s attitudes to working and what stops them.

8.9.3 Investigation of why people with schizophrenia work in the occupations they do

Although some people with schizophrenia work in nearly all sections of the labour market, most work in elementary or semi-skilled occupations. As suggested these types of role may involve low levels of inter-personal interaction, which some authors argue people with schizophrenia have a

propensity to work in (Bacani-Oropilla et al 1991). Additionally a lack of skills or discrimination in the labour market may play a part in explaining this.

A more complex understanding of the reasons for occupational patterns may enable the development of targeted interventions or more specific training to help people work in the jobs that they aspire to. These might be more beneficial than generic prevocational training and this may especially be the case early in illness course.

8.9.4 Further investigation of the factors associated with employment

We are beginning to understand the factors that might be associated with employment in people with schizophrenia though the results of multiple studies are not always consistent. The influence of many variables, including gender, age, marital status, depressive symptoms and medication side effects, remains unclear, either because the literature does not yet present any discernible pattern, associations are changeable or they have not been widely tested.

Further studies require some degree of consistency in the definition of employment used, the time period over which working is coded (e.g. over the last month or 6 months) and the length of employment tenure investigated. Additional comparable studies would allow the completion of a more robust meta-analysis than has hitherto been possible (Wewiorski and Fabian 2004).

8.9.5 Exploration of the factors associated with losing a job

Very little epidemiological evidence is currently available to illuminate the reasons why people with schizophrenia lose a job. Although requiring replication, the findings from the EuroSC study that alcohol misuse and higher levels of positive psychotic symptoms at baseline increased the odds of losing a job and that vocational training is protective add substantially to the current literature. This is an under-researched area, even though suitable data for analysis may be available from the large number of evaluations of supported

employment programmes that have now been completed (Drake et al 1999b, Lehman et al 2002, Cook et al 2006, Burns et al 2007). Further evidence from naturalistic studies would further aid our understanding also.

8.9.6 An examination of the dynamic process factors associated with getting a job and losing a job.

The literature is lacking in explorations of the dynamic process factors associated with a change in employment status. For example we know little about the circumstances of people when they decide to apply for work and as they get employment. What factors stimulate the motivation for finding work is a potentially intriguing area for further quantitative and qualitative research. Examples that might be important but are largely unexplored are the level of satisfaction with life, the number and quality of social relationships, life expectations or level of positive reinforcement that a person receives if they discuss a desire to work by friends and family.

Equally we understand very little about the contexts and processes surrounding job loss in people with schizophrenia. Even the very basic question of how often people with schizophrenia leave a job because of illness, poor performance, discrimination or other causes remains unclear, although the limited available evidence suggests all may be important (Becker et al 1998)

8.9.7 Further exploration of the effect of working on other outcomes

Employment may result in positive non-vocational outcomes. Further studies are required which control for the wide range of other factors that may influence outcomes such as quality of life, psychotic symptoms and general functioning and that can better identify the causal direction. Also a key hypothesis that specifically needs to be tested is whether working plays any part in relapse of severe mental illness, a point of concern for both staff and people with schizophrenia. The current evidence would suggest not (Chapter 5), at least for relatively short periods of work. It is possible to speculate that

more constant and longer-term employment may. Time series analysis of prospective data would be suited to answering these questions.

8.9.8 Understanding current specialist employment services

Though there is evidence that might guide vocational service development in the UK, implementing change in a coordinated way may be difficult because of the wide range of agencies that seem to provide employment services for the mentally ill. We do not know how many organisations are delivering vocational assistance in the UK or how they do this. It has been estimated that in 1999 in the UK around 30% of the organisations providing vocational services had open market employment as their goal (Grove & Drurie 1999, Crowther et al 2001). What proportion of these used supported employment programmes is unclear. Also at around this time there were 135 schemes providing sheltered employment and around 50 organisations that were described as social firms.

In order to plan a strategy of vocational service development we need to understand what is available currently in the UK in a much more comprehensive way than is currently the case. In short services need to be mapped. Potential areas of interest might be the funding source of the service, whether the aim is open market employment, model of intervention used and who is excluded and catered for within each service.

8.9.9 Development and evaluation of interventions to reduce barriers to working

Although knowledge of the barriers to working that people face is now rapidly developing, what the literature lacks is investigations of what factors are most important, and also which are potentially amenable to change. Target areas might include developing interventions to challenge discrimination and stigma in the labour market, investigating the effectiveness of changing the earnings disregard or making information about benefit payments and employment more accessible to clinicians and service users.

8.9.10 Further evaluation of vocational services

Although supported employment in the form of IPS is effective, a significant number of people do not have a good outcome from this model of service provision. Further development and testing of models that might improve the outcome for this group as well as for those people who do not engage in IPS is necessary. Obvious targets for further evaluation are social firms.

8.9.11 Additional surveys of employer attitudes

People with schizophrenia report discrimination by employers as a reason for difficulties in getting work. To date only one previous study (Manning & White 1995) has directly asked employers for their views. Replication is required not only to confirm results but also to further enhance our understanding of what makes employers choose to support people with mental health problems as well as dismiss them.

8.9.12 Assessment of capacity for work

Assessing capacity for work is likely to become increasingly important in the UK with the enactment of the Welfare Reform Act 2007. Standardised, valid and reliable assessments may need to be developed if the rights of people with severe mental illness to work or claim sufficient benefits are to be safeguarded. Though the act requires such assessments to be done, the extent to which these have been developed rigorously using the limited evidence base is currently unclear.

Given that many of the evaluations of IPS do not formally assess peoples capacity for employment but are effective in helping people gain jobs, it may be that motivation to work is equally or more important than any assessment of capacity to work.

8.10 Conclusion

Although the rates of employment of people with schizophrenia are low, international and regional variations in rates suggest that unemployment does not have to be the natural result of this illness. Substance misuse, continuous illness course, positive and negative and non-psychotic symptoms all damage employment prospects, although the size of the effect especially for symptoms does not appear to be large. Area of residence, general population employment rates and higher educational attainment also explain employment status. The availability of vocational services appears to affect whether people work.

There are many barriers to working, and some people with schizophrenia do not feel choosing to work is open to them or is the best course of action given the multiple impediments they face. Patient experiences and concerns are echoed to some extent by clinician attitudes. Although the biological features of schizophrenia have an important influence on employment prospects, there are multiple significant factors that are social or societal also. Thus unemployment in people with schizophrenia appears to be the consequence of interplay between people's biological and social characteristics, their situations and societal factors that affect their choices and efforts. Promisingly this also means that there are multiple points at which interventions may be effective and help people to work.

Chapter 9

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Appendix A. Abbreviations used in this thesis

CMHT	Community Mental Health Team
US	United States of America
GAF	Global Assessment of Functioning
QOLI	Lehman's Quality of Life Interview
QOL	Quality of life
PANSS	Positive and Negative Syndrome Scale
CDSS	Calgary Depression Scale for Schizophrenia
UK	United Kingdom
EuroSC	European Schizophrenia Cohort
SCAN	Schedule for Clinical Assessment in Neuropsychiatry
WHO	World Health Organization
SMI	Severe mental illness
GDP	Gross Domestic Product
IPS	Individual Placement and Support
RCT	Randomised controlled trial
OECD	Organisation for Economic Co-operation and Development
GP	General Practitioner
DSM	Diagnostic and Statistical manual
ICD	International Classification of Disease
ANCOVA	Analysis of Covariance
ANOVA	Analysis of variance
IPSS	International Pilot Study of Schizophrenia
BPRS	Brief Psychiatric Rating Scale
GAS	Global Assessment Scale
APA	American Psychiatric Association
PHSD	Past History and Socio-demographic Description Schedule
ROMI	Rating of Medication Influences Scale
ESMS	European Service Mapping Schedule
DUP	Duration of untreated psychosis
BPAD	Bipolar Affective Disorder

Appendix B:

Instruments used in the EuroSC study from which data was analysed in this thesis

The Lehman's Quality of Life Interview (QOLI)

The QOLI assesses subjective and objective quality of life in 8 different areas. These are living situation, daily activities and functioning, family, social relations, finances, work and school, legal and safety issues and health. It also provides a satisfaction with life in general subjective rating of QOL. Answers to the subjective QOL questions are rated on a 7-point Likert Scale where 1 equates to *terrible* and 7 to *delighted*. Satisfaction with life in general is rated at the start of interview and then at the end and the mean of these two scores is often used as a broad measure of subjective QOL. The objective QOLI information was not used. The psychometric properties of the QOLI are well established and have been extensively investigated. Construct and predictive validity has been reported to be good using confirmatory factor analyses and multivariate predictor modelling (Lehman 2001)

Positive and Negative Syndrome Scale (PANSS)

The PANSS comprises 30 items, each rated on a 7-point scale of severity. There are detailed instructions for conducting the clinical interview on which the ratings are based, and a glossary of individual items (Kay et al 1989). Seven items provide an overall positive syndrome score, seven a negative syndrome score, and sixteen a general measure of psychopathology. Inter-rater reliability has been reported as adequate or good (Bell et al 1992, Norman et al 1996) and there is evidence of criterion related validity (Kay et al 1987).

Calgary Depression Scale for Schizophrenia

This researcher administered questionnaire has been designed specifically to measure depression in patients with schizophrenia. It is composed of nine questions, rated on a four-point scale. A global score is obtained by adding the values scored for each item and this summary score ranges between 0-27. Its reliability and construct validity are good and its divergent validity from positive, negative and extra-pyramidal symptoms has been established (Addington et al 1994). A score of 6 or more was used to indicate depression in this thesis, as suggested by Addington et al (1996). This cut-off has a specificity of 77% and a sensitivity of 92% to detect a major depressive episode (Addington et al 1993).

The European Service Mapping Schedule (ESMS)

The ESMS is an instrument developed to describe and classify mental health services and to measure service use. Its use has been described as feasible in several European countries (Johnson & Kuhlmann 2000). The ESMS classifies employment services as high intensity (available for patients to attend for at least 4 half days a week) or low intensity (patients usually attend for less than 4 half days a week). Secondly services are split into “work” services and “work related activity” services. Work services are defined as those which provide the opportunity for patients to work with pay of at least 50% of the usual local minimum expected wage for this form of work but which has not been obtained through fully open competition. Work related activity (WRA) services are defined as those services where patients carry out an activity, which closely resembles work for which payment would be expected in the open market. In such services patients are either not paid or paid less than 50% of the usual local expected wage for this form of work.

Rating of Medication Influences (ROMI) Scale

The ROMI was used to evaluate adherence (Weiden et al 1994). It is a reliable and valid standardised measure for the assessment of attitudinal and behavioural factors influencing patients' adherence to anti-psychotic treatment (Weiden et al 1994). It assesses the patients' own reasons for medication adherence and non-adherence and produces two summary scores; the reasons for compliance; and the reasons for non-compliance score.

Schedule for Clinical Assessment in Neuropsychiatry (SCAN)

The SCAN (Wing et al 1990, WHO 1992) includes the 10th edition of the Present State Examination (PSE) and is a semi-structured clinical instrument for describing psychopathology. The aims of the SCAN are to "provide a comprehensive, accurate and technically specifiable means of describing and classifying phenomena in order to make comparisons" (Wing & Brugha 2001). It and the PSE were developed to enhance the reliability of psychiatric diagnosis. The SCAN covers the diagnostic items of the ICD-10 and the DSM-III-R. Raters receive standardised training in an attempt to ensure reliability. Trials conducted in 14 countries suggest reliability is good (WHO 1992)

On all occasions the SCAN was used to evaluate the 4-week period before interview in the EuroSC study.

Structured Clinical Interview for DSM-IV (SCID)

The SCID –DSM-IV (First et al 1997) is a semi-structured interview for making the major DSM-IV Axis 1 diagnosis. It is designed to be administered by a trained clinician. The patient version used in the EuroSC study was developed for usage with people who have already been identified as psychiatric patients. For making a diagnosis of schizophrenia reliability has been reported as good to high (Skre et al 1991, Williams et al 1991)

Global Assessment of Functioning (GAF)

The Global Assessment of Functioning (GAF) scale (American Psychiatric Association, 1994) provides an evaluation of the overall level of psycho-social functioning for people with psychiatric disorders, with detailed descriptions acting as anchor points. It is a clinician rating on a scale of 0-100 where a higher score indicates better functioning. GAF ratings are substantially associated with severity of psychiatric diagnosis and the extent of symptoms (Brekke 1992, Coffey et al 1996, Coulehan et al 1997) and are modestly associated with some indexes of social functioning (Moos et al 2002)

Past History and Socio-demographic Description Schedule (PHSD)

This instrument was used in the WHO Collaborative Study on the Assessment and Reduction of Psychiatric Disability, and the adaptation used in the EuroSC study was based on the third draft of 1977. The PHSD collects information on educational level, employment status, details of family members and living situation. The instrument has been widely used since the WHO study (Marneros et al 1989, Rossler et al 1999) and is often harmonised if used in international studies (Kovess et al 2006)

Appendix C

Interview Guide. Views and experiences of employment among people with psychosis: a qualitative descriptive study

- What work would mean for the person?

Do you want to work?

What kind of work would you like to do?

Do you think there are advantages/disadvantages to working?

- How does illness affect ability to work?

What potential problems would there be with you working?

How might your mental health problems affect your ability to work?

Would you find it difficult to work?

- What are the perceived barriers to finding work?

What stops you working?

Have you tried to look for work- any problems?

Would you have particular worries about getting paid work?

What worries do you think employers would have in hiring you?

Would you tell them you had a mental health problem?

- Current service provision

Have you had contact with services that to get you back to work?

Have you had experience of sheltered or voluntary work-what was it like?

Did it prepare you for competitive employment?

How did it affect your views on getting paid work (if appropriate)?

Have you had experience of competitive work?

What was it like working?

What happened when you stopped working?

Where would you go to get help with finding a job?

Are there particular kinds of help you need in getting work because of your health problems?

Is the help available at the moment that you believe is needed?

What help is not provided that could be?

Appendix D

Questionnaire. Staff attitudes to people with a psychotic disorder working

Questionnaire Number.....

Staff attitudes to people with a psychotic disorder working.

Please could you fill in the questionnaire below thinking about the questions with reference to people with a psychotic illness (eg schizophrenia, bipolar disorder etc) on your caseload. There are no right or wrong answers so please be as honest as possible. Your responses will be confidential. The questionnaire will probably take around 5-10 minutes to complete.

Unless stated otherwise work refers to full-time paid employment.

Your details

What is your profession (eg nurse, OT, psychiatrist, social worker, psychologist, nursing assistant, support worker)

.....

Age:

Team (please circle): CMHT Crisis team AOT Rehabilitation EIS

Sex (please circle): Male / Female

Area (please circle): South Camden North Camden S Islington N Islington

How long have you been qualified in your profession?.....

How many people do you have on your caseload with a psychotic disorder

Questions

1. In your view how many people with a psychotic disorder on your caseload are capable of doing the following types of work?	Full-time	Part time (< 4 days)	Voluntary/ Sheltered work	Incapable of work
2. How many people with a psychotic disorder on your caseload are in the following types of employment?	Full-time	Part time only	Full-time Voluntary / Sheltered only	Part time Voluntary / Sheltered only
3. Of those who could manage paid work how many people with a psychotic disorder on your caseload are capable of doing the following jobs given the appropriate training?	Marketing manager	A computer programmer	Nursing assistant	Library assistant
Of those who could manage paid work how many people with a psychotic disorder on your caseload are capable of doing the following jobs given the appropriate training?	Child minder	A sales Assistant	Gardener	A police cadet

4. The following is a list of potential benefits of working to people with a psychotic disorder. Please rate how important you think these advantages would be to service users in practice?	Not at all	Slightly important	Quite important	Very Important
Providing day time structure	1	2	3	4
More money	1	2	3	4
Having a role in society	1	2	3	4
Autonomy and independence	1	2	3	4
Working being good for the person's mental health	1	2	3	4
Opportunity to meet other people outside of mental health services and family	1	2	3	4
Confidence and self esteem	1	2	3	4
Reducing the level of drug and alcohol use	1	2	3	4

5. The following is a list of potential difficulties for people with psychosis to work. Please rate how important you think these are as barriers in practice?	Not at all important	Slightly important	Quite important	Very important
The benefits trap(needing a wage equal to or more than benefits to make it worthwhile financially)	1	2	3	4
The worry / fear that the stress of work might lead to a relapse	1	2	3	4
The effects of taking medication	1	2	3	4
Low energy and volition	1	2	3	4
Stigma associated with mental illness	1	2	3	4
Lack of specialist services to help people back to work.	1	2	3	4
Positive symptoms of psychosis (delusions and hallucinations)	1	2	3	4
Lack of jobs suitable for people with psychosis in the current labour market	1	2	3	4
Lack of encouragement and support in returning to work	1	2	3	4
Over-reliance on state benefits.	1	2	3	4
People saying they want to work but not actively seeking a job	1	2	3	4
People repetitively failing to get jobs they apply for	1	2	3	4
Drug / alcohol misuse	1	2	3	4
Other (please write down any others)	1	2	3	4

6. If you think someone is capable of employment how much of a role do you play in facilitating this?	Not at all, (its not my job)	A little	Quite a lot	A priority in my role.
7. Assuming you think someone with a psychotic disorder can work how much importance would you give to referring them to employment services as part of your role?	No importance	A little importance	Quite a lot of importance	A great deal of importance
8. In your normal practice, if you think some one with a psychotic disorder could work how much do you discuss this with them?	Very little	Occasionally	A substantial amount	It tends to be the main focus of a number of meetings
9. A person on your caseload who is an office manager has just been discharged from hospital following a psychotic episode. He no longer has any substantial symptoms. He asks when he should return to work. On average how long would you suggest someone in this situation should "rest", before trying to return to work?	A couple of months maximum	2- 6 months	6-12 months	More than a year
10. A person on your caseload who is a plumber has just been discharged from hospital following a psychotic episode. He no longer has any substantial symptoms. He asks when he should return to work. On average how long would you suggest someone in this situation should "rest", before trying to return to work?	A couple of months maximum	2- 6 months	6-12 months	More than a year
11. How confident do you feel in assessing someone's capacity for paid work?	Not confident	Low confidence	Quite confident	Very confident

12. In your education or career how much training have you had in assessing someone's capacity for paid work?	Practically none	Up to 2 days	2-7 days training	More than 7days training
13. If you have had some training how effective do you think it has been, in equipping you to make an assessment of someone's ability to do paid work?	Not very effective	Slightly effective	Quite effective	Very effective
14. How much time do you think it would be worth you devoting to such training?	Not worthwhile for me	2 hour workshop	1 day workshop	1 week course-workshop
15. How clear are you or how much do you know about what specialist employment services for people with psychosis are available locally?	Not very clear	Some idea of what is available	A good idea of what is available	Very clear about what is available
16. How effective do you think local mental health services (including specialist employment services) are, in getting people back to paid work?	Not very good	Slightly effective	Quite effective	Very effective
17. How high a priority should local mental health services put on getting people back into paid employment?	Not at all	A small priority.	Some priority	A high priority
18. How much of a role do you think mental health services should play in facilitating a return to work? Put the following in order of the priority you would give to each (1= most important, 4= least important)	Training to all staff on vocational support 	A vocational worker 	A vocational rehabilitation centre 	A substantial service that helps find work for people with a psychotic disorder and supports them in it

19. Assuming the costs were the same but there was funding for only one write down the priority you would give to the following different services. (1= highest priority, 4= lowest priority)	A dual diagnosis service 	Better services for people with personality disorders 	Improving inpatient services 	A substantial service that helps find work for people with a psychotic disorder and supports them in it
20. How useful do you think mainstream employment services (eg Jobcentre, Connexions etc) are in getting people with a psychotic disorder back to paid work?	Not useful	A little useful	Quite useful	Very good

Finally is there anything else you would like to say about people with a psychotic disorder and work?

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Thank you very much for completing this questionnaire